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Pain Management Experiences in Adults Living with HIV/AIDS

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Pain Management Experiences in Adults Living with HIV/AIDS

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Dedication

I dedicate my dissertation to the many lives affected by this chronic illness and those individuals who live with chronic pain. The human immunodeficiency virus (HIV) has been present worldwide since its recognition in 1981 afflicting more than 33.3 million people by the end of the year 2009 (UNAIDS *AIDS Epidemic Update*, 2010*)*. In the early days of the AIDS epidemic, patients quickly became bedbound, incontinent, and paralyzed; they died within a matter of days. The HIV epidemic in America has evolved scientifically, socially, culturally and politically over the past 30 years.

Due to advances in medication management, the lethality of the AIDS epidemic is a distant memory; however, the disease now requires daily treatment and remains an incurable and frequently disabling condition. Although the medications have offered miracles, for some, those miracles are not a lasting solution to managing their illness. This 'miracle' comes with a high price. Their lifelong medication commitment often reaches a breaking point; after living and struggling for many years with constant stress and adversity, they have a longer life, but it's a life in crisis. Many people are on medical disability and are acutely aware of the lives they are unable to lead due to both the limits HIV/AIDS places upon them and their chronic, unrelenting pain.

This population experiences not only the physical trauma of constant pain, but also an additional level of stress and adversity when they seek care; the stigma of chronic pain. Working with the Austin HIV/AIDS community over the past six years has been a fulfilling experience. From the very beginning, it was clear that there is a large number of HIV-positive adults who are living and coping with constant pain. Many in this

population have lost scores of friends to the AIDS epidemic; having outlived them, they now silently suffer in pain alone.

Their voice in this world is respected and valued. Thank you.

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I also thank the many faculty and staff at the School of Nursing who have taught me and worked with me when I served as a teaching assistant and provided me with many opportunities and experiences that have made me the professional I am today.

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Pain Management Experiences in Adults Living with HIV/AIDS

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The University of Texas at Austin, 2011

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Abstract: Even though pain is common and often chronic in people living with HIV/AIDS (PLWHA), the management of pain is complicated and frequently woefully inadequate. Many factors influence the way PLWHA experience and communicate their pain. These factors can be categorized as both physiological and emotional. PLWHA often resort to self-care activities to control their pain because of the pervasive lack of adequate pain management by health care providers. The purposes of this study were to increase understanding of the pain management experiences in people living with HIV/AIDS (PLWHA) who report chronic pain and to elucidate the factors that influence this experience. Recruitment was conducted at 3 locations in Central Texas, USA; serving over 3,000 clients/year. A cross-sectional descriptive design and open-ended questions were used to explore PLWHA experiences in reporting chronic pain needs for at least 3 months and to describe pain management choices (self-care and/or seeking care activities) and communication with health care providers. Variables of interest were assessed with paper-pencil surveys (HIV-Self Efficacy Questionnaire, Coping Inventory for Pain in Persons Living with HIV/AIDS and Pain Self-Efficacy Questionnaire) and open-ended questions. Interviews ranged from 7-35 minutes each. One hundred PLWHA participated in the study, 53% African-American, 21% Hispanic and 25% Caucasian. They were primarily male (66%), 34% female, reported a mean age of 48 years and a

mean of 13 years living with HIV. 83% of the participants rated their pain as consistently moderate to high levels; 82% rated they are likely to "tolerate the pain." A majority of the participants (63%) reported they exercise or walk as a way of self-managing their pain. There was a significant association between use of pain management choices (self-care and/or seeking care activities) and confidence in performing life activities (r= 0.344, p<0.05). These findings indicate a need for health care providers to move beyond quantitative measures for this complex problem. Clinicians can use this information to understand the coping strategies used by PLWHA to manage pain. Future implications will be to develop appropriate pain management approaches (behavioral and pharmacological) for healthcare providers to improve control of chronic pain in PLWHA. Longitudinal studies are needed to explore the causative relationships between pain management choices (self-care and/or seeking care activities) and functional outcomes in PLWHA.

Table of Contents

List of Tables

List of Figures

CHAPTER 1: INTRODUCTION

Even though the population of adults who live with Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) is growing, people living with HIV/AIDS (PLWHA) remain stigmatized and marginalized worldwide, which can influence the choices available to them for symptom management. One of the most common symptoms PLWHA face daily is pain. Chronic pain is pain that lasts more than three months (Bonica, 1990). Chronic pain has been linked to decreased daily physical functioning (Breitbart, et al., 1996; McCarberg, Nicholson, Todd, Palmer, & Penles, 2008), increased depression and negative thoughts (Evans, Weinberg, Spielman, & Fishman, 2003), and increased number of HIV-related symptoms (Coulter, et al., 2002).

Many factors can influence the way PLWHA experience and respond to the symptom of pain. These factors can be broadly categorized as both physiological (e.g., pain symptoms and overall state of health) and emotional (e.g., communication, coping and stress of everyday living). Even though pain is common and often chronic in this population (O'Neill & Sherrard, 1993), the management of pain is complicated and frequently woefully inadequate (McCormack, Li, Zaroway & Singer, 1993; Vogl, et al., 1999). Because of the pervasive lack of adequate pain management by health care providers, PLWHA often resort to self-care activities to control their pain.

The symptom of pain in PLWHA has been the focus of research for many years (Breitbart, et al., 1996). Singer, et al. (1993) explored pain symptoms in PLWHA. Using quantitative methods Singer and colleagues demonstrated that pain is complex and widespread in PLWHA. O'Neill, et al. (1993) found that nearly all organ systems are targeted by HIV creating a variety of pain symptoms as virus progression occurs.

Recommendations for pain management in PLWHA broadly follow the World Health Organization's (WHO) criteria for treating pain in cancer patients (Jadad & Browman, 1995). This three-step analgesic ladder includes: non-opioid, opioid for mild to moderate pain, and opioid for moderate to severe pain along with the use of adjuvant medications. Since the WHO analgesic ladder was created over 25 years ago, there have been studies that have evaluated its use and effectiveness in cancer patients. Most recently, Ferreira, Kimura and Teineira (2006) reviewed the literature and found that out of 292 available abstracts, only 17 met the criteria for eligibility. From the studies reviewed, Ferreira, et al. (2006) determined that pain is subjective and complete pain relief is often not achieved, but pain can be reduced in patients. They concluded that clinicians can provide treatment of the symptom of pain by using the WHO analgesic ladder given that clinicians have appropriate knowledge of side effects of medications and interactions listed for medications on the ladder.

It must be noted that pain in PLWHA is often multi-factorial and thus needs to be thoroughly investigated by health care providers. Pain symptoms have been found to impact the daily functioning of all individuals who experience it; however complaints of pain in PLWHA are often disregarded by health care providers as drug seeking behaviors and thus complaints do not receive medical intervention (Breitbart, et al., 1996; McCormack et al., 1993).

The studies conducted in the early 1990's provide evidence of the pervasive and complex nature of pain symptoms in PLWHA, as well as the appalling lack of adequate pain management intervention by health care providers. However, these quantitative studies fail to explicate several aspects of the PLWHA's experience with pain symptoms. Specifically, the current literature fails to provide an understanding about the influence of PLWHA's self-efficacy to communicate with health care providers about their pain and

their particular pain management choices (self-care and/or seeking care activities) on the PLWHA's confidence to perform life activities while experiencing pain.

This study describes the relationships between these variables (communication self-efficacy, pain management choices (self-care and/or seeking care activities), confidence in performing life activities) in PLWHA who experience chronic pain. The knowledge gained in this study may be helpful in understanding the PLWHA's pain management needs as well as the barriers they experience that can influence adequate pain management by health care providers.

PURPOSE OF THE STUDY

The purposes of this study were to increase understanding of the pain management experiences in PLWHA who report chronic pain and to elucidate the factors that influence this experience. A better understanding of the relationships among health care provider stigma, past health care experiences, self-efficacy in communicating pain to health care providers, pain management choices (self-care and/or seeking care activities), and confidence in performing life activities in PLWHA will allow for future development of appropriate pain management approaches by health care providers when caring for people living with the chronic illness of HIV/AIDS.

BACKGROUND OF PROPOSED STUDY

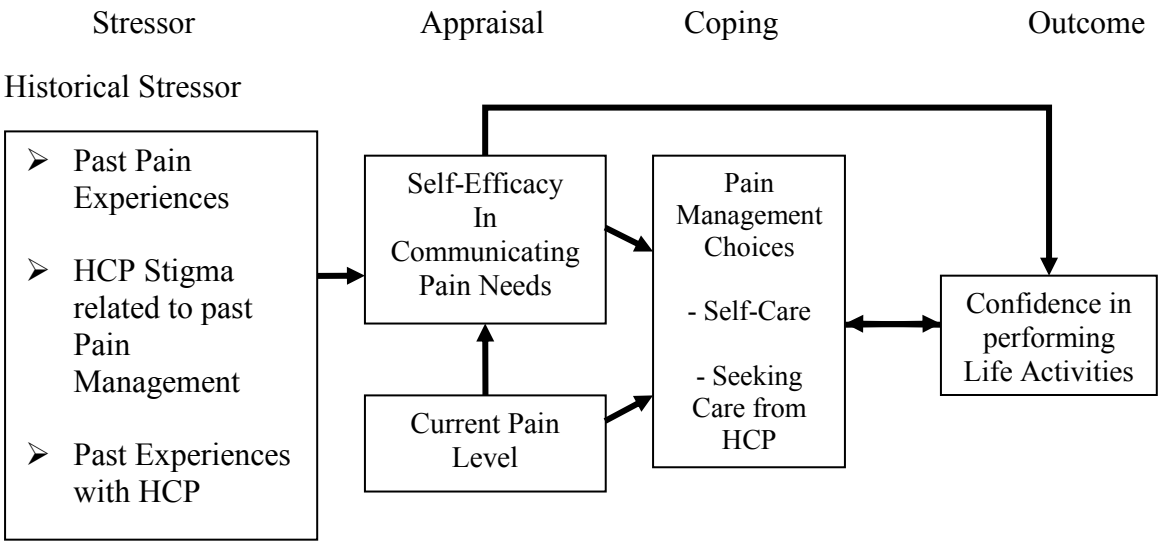
Conceptual Model

Lazarus and Folkman's Stress, Appraisal and Coping Model (1984) guided this study. The stress process model indicates that a stressor causes a person to appraise the threat associated with the stressor and to determine if s/he has the ability to cope with this

threat. According to the model, if the individual is able to effectively cope with the threat, a positive outcome may be experienced. The model has been adapted for the present research study to explore the relationships among the variables of interest for pain management in PLWHA.

The research model for the present study is illustrated in Figure 1. A summary of the literature supporting the relationships depicted in the model is presented following the model. A full discussion of the literature is presented in Chapter 2.

Figure 1. Conceptual Model for Pain Management in PLWHA



Stressors (Historical Stressor)

In PLWHA who have chronic pain, health care provider stigma and past experiences when communicating pain needs to the health care provider are historical stressors. These historical stressors may influence how the PLWHA will appraise self-efficacy in communicating pain needs during subsequent pain experiences. Historical stressors may also influence the decisions PLWHA make regarding pain management

choices (self-care and/or seeking care activities) when experiencing subsequent pain through the influence they have on the PLWHA's self-efficacy in communicating their pain needs to the health care provider.

Appraisal

If health care provider stigma and/or negative past experiences with communicating pain needs and chronic pain are present (historical stressors), the PLWHA may experience poor (low) self-efficacy in communicating their pain needs to health care providers. If health care provider stigma and/or negative past experiences with communicating pain needs are <u>not</u> part of the PLWHA's historical context, the PLWHA may experience good (high) self-efficacy in communicating their pain needs to health care providers.

The current pain levels of chronic pain sufferers negatively impact activities of daily living which impact many aspects of their lives from personal relationships to mental health (McCarberg, et al., 2008). Therefore, current pain may also influence the PLWHA's appraisal of their self-efficacy to communicate their pain needs.

Coping

If PLWHA experiences poor (low) self-efficacy with communicating pain needs, they may choose to treat their pain in ways that may be less effective in controlling their pain (Evans, et al., 2003; Stroud, et al., 2000). For example, massage, praying (distraction methods), taking previously prescribed medication, drinking alcohol or using illegal narcotics are all self-care activities that PLWHA have reported using to manage their pain symptoms. PLWHA who choose only self-care activities may become 'silent pain

suffers' coping with their pain in any way possible (Watkins, Wollan, et al, 2006; Samwell, et al., 2006). Whereas, if the PLWHA experiences good (high) self-efficacy with communicating pain needs to their health care provider, they may choose to seek care from physicians, registered nurses, and/or occupational therapists who can partner with the PLWHA to manage their pain symptoms (Robb, et al., 2006). However, little is known about the factors that motivate a PLWHA to choose to seek care from health care professionals for pain management.

Outcomes

Finally, the outcome of adequately managed pain is a sense of increased confidence the PLWHA has in performing life activities within the context of pain (Asghari & Nicholas, 2001; Jensen, Turner & Romano, 1991; Nicholas 2007). Again, little is known about the cascade of influences that result in PLWHA's ability to carry on with life activities in the context of chronic pain. It is acknowledged that chronic HIV related pain is never 'completely gone'. The goal is to manage the pain in such a way that the level of pain allows the PLWHA to carry out their daily activities even within the context of that pain.

SIGNIFICANCE

Approximately 30%-80% of the adult HIV population experiences pain as a daily symptom (American Psychiatry Association Office on HIV Psychiatry and Pain, 2000; Vogl, et al., 1999). HIV/AIDS is a chronic illness that has been studied, evaluated, and tracked on many levels by both the scientific and federal communities; however, there is a dearth of literature describing what choices PLWHA make to manage their chronic pain symptoms and the factors that influence these choices. What data are available come

from quantitative studies that fail to capture the voice of the PLWHA on this important topic. This study attempts to address some of these gaps in the current literature.

In this study, the PLWHA's historical stressors and the influence these stressors have on the PLWHA's self-efficacy in communicating their pain needs to health care providers are described. In addition, the choices that PLWHA make to manage their chronic pain symptoms are described. Finally, the relationships among the historical stressors, self-efficacy in communicating pain needs, pain management choices (self-care and/or seeking care activities), and the resulting confidence in performing life activities within the context of pain are explored and described.

This information can be used by health care providers to understand the PLWHA's pain management needs as well as the barriers these patients experience when attempting to receive adequate pain management. This knowledge provides a baseline for continued research and investigation of symptoms experienced within the chronic illness of HIV and the barriers to care perceived by the PLWHA.

STATEMENT OF THE PROBLEM

The specific aims of the study were 1) to describe PLWHA's self-efficacy in communicating their pain needs to health care providers, pain management choices (self-care and/or seeking care activities) and PLWHA's confidence in performing life activities within the context of pain, 2) to describe the influence of health care provider stigma and past health care experiences on the PLWHA's self-efficacy in communicating pain needs to the healthcare provider, 3) to explore the relationships between PLWHA's self-efficacy in communicating pain needs and their pain management choices (self-care and/or seeking care activities), and 4) to explore the relationships between PLWHA's

pain management choices (self-care and/or seeking care activities) and confidence in performing life activities within the context of pain.

RESEARCH QUESTIONS

The research questions addressed in this study were:

1. How do PLWHA describe their self-efficacy to communicate their pain needs to health care providers, their pain management choices (self-care and/or seeking care activities), and their confidence in performing life activities within the context of pain?
2. What are the influences of health care provider stigma and past health care experiences on PLWHA's self-efficacy to communicate pain needs to their health care providers?
3. What are the relationships between PLWHA's self-efficacy to communicate pain needs to health care providers and their pain management choices (self-care and/or seeking care activities)?
4. What are the relationships between PLWHA's pain management choices (self-care and/or seeking care activities) and their confidence in performing life activities within the context of pain?

DEFINITIONS OF TERMS

For the purposes of this study, the following definitions were used:

1. Human Immunodeficiency Virus (HIV) – a virus that causes Acquired Immunodeficiency Syndrome (AIDS) which "attacks and destroys the disease fighting cells of the immune system, leaving the body with a weakened

defense against infections and cancer," (www.aidsinfo.nih.gov, retrieved September 1, 2008). The virus is passed from person-to-person when infected "blood, semen, or vaginal secretions come in contact with an uninfected person's broken skin or mucous membranes," (www.cdc.gov, retrieved September 1, 2008).

2. People Living with HIV/AIDS (PLWHA) – persons diagnosed with HIV/AIDS who may or may not be receiving treatment which includes the use of highly-active anti-retroviral therapy (HAART). (www.aidsinfo.nih.gov, retrieved September 1, 2008).
3. Historical Stressors – "the experience of a perceived threat (real or imagined) to one's mental, physical or spiritual well-being, resulting from a series of physiological responses and adaptations," (Seaward, 2009, p. 3). Historical stressors for this study were identified as health care provider stigma, chronic pain, and past health care experiences of pain management for PLWHA.

3A. Past Pain Experiences are any previous experiences the participant has had when interacting and/or communicating with health care providers when coping with the symptom of pain.

3B. Health Care Provider Stigma related to Past Pain Management – "an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society," (*Health Resources and Services Administration (HRSA)*, 2004, p. 2). Stigma related to PLWHA's experiences during past pain management interactions with health care providers is the focus of this study.

3C. Past Experiences with Health Care Provider – Thoughts and feelings about previous encounters with health care providers when receiving care for HIV/AIDS-related pain symptoms.

4. Appraisal – "the individual's subjective interpretation of a transaction," (Lazarus & Folkman, 1984, p. 46).

4A. Self-Efficacy – "an individual's confidence in his or her ability to perform a task or accomplish an outcome" (Bandura, 1986).

4B. Self-Efficacy in Communicating Pain Needs is the PLWHA's confidence in his or her ability to communicate pain needs to their health care provider in order to manage their pain.

4C. Current Pain Level is the rating of chronic pain reported by the participant using the "0 to 10 Numeric Pain Intensity scale.

4D. Chronic Pain -- "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (International Association for the Study of Pain, 1994). Chronic pain can develop as disease progression occurs in PLWHA. Chronic pain is pain that lasts longer than three months (Bonica, 1990).

5. Coping – "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person," (Lazarus & Folkman, 1984, p.141).

5A. Pain Management Choices -- self-care and/or seeking care activities that PLWHA use in order to cope with chronic pain symptoms.

5B. Self-Care Activities – refers to when PLWHA with chronic pain attempt to lessen their chronic pain symptoms without seeking professional medical care. Examples of self-care activities include but are not limited to:

praying, taking a bath, massage, acupuncture, reading or watching TV, taking medications previously prescribed for other conditions, or over-the-counter medications, or using alcohol or illicit drugs, or similar activities.

5C. Seeking Care Activities – refers to when PLWHA with chronic pain attempts to manage their chronic pain symptoms by seeking professional medical care. Examples of 'seeking care' include but are not limited to: visiting a medical doctor (MD), doctor of osteopathy (DO), advanced practice nurse (APN), pain specialist or pain management programs.

6. Outcomes – "something that follows as a result or consequence," (www.merriamwebster.com, retrieved September 1, 2008). When the PLWHA's pain symptoms are adequately managed, there is a positive outcome of increased confidence to perform life activities within the context of pain.

6A. Confidence in Performing Life Activities within the Context of Pain – "a person's confidence in being able to perform life activities despite pain," (Asghari & Nicholas, 2001, p. 98). Specifically, "a person's perception of their ability to accomplish life activities despite the presence of pain," (Asghari & Nicholas, 2001, p.98).

ASSUMPTIONS

The following assumptions were made in the current research study:

1. PLWHA experience pain,
2. Several physiological and emotional factors influence how PLWHA experience and respond to the symptoms of chronic pain,

3. PLWHA may experience stigma in interactions with healthcare providers regarding pain management,
4. PLWHA will be willing to talk to the researcher about their experiences with pain management; and answering questions (qualitative and quantitative) honestly,
5. Seeking professional help to manage pain is more effective than self-care activities.

LIMITATIONS

Possible limitations of the present study include the following:

1. The sampling method was self-selected convenience sampling. The participants may not have accurately reflected the status of all PLWHA, however, the final sample is representative of the Central Texas HIV/AIDS population (Trochim, 2001).
2. Data were obtained through self-report measures, which according to Polit and Beck (2004), may be subject to accuracy and validity concerns. There is no guarantee the sample responded honestly. Additionally, the self-assessment of confidence in performing life activities is less objective than performance-based measures of confidence.
3. Generalizations of the results are limited to PLWHA with chronic pain. Thus, generalizations of other chronic illness populations that experience chronic pain should be made with caution and take age and demographic backgrounds into account.

4. The cross-sectional nature of this study does not allow for inference of causality between variables.
5. The contribution of co-morbid conditions to the confidence in performing life activities was not addressed in this study.

SUMMARY

In this chapter, the purpose, background, significance, statement of the problem, research questions and definition of terms and assumptions were described. The purposes of this study were to increase understanding of the pain management experiences in PLWHA who report chronic pain and to elucidate the factors that influence this experience.

Lazarus and Folkman's Stress, Appraisal and Coping model (1984) served as a guide for this study. This model was chosen because PLWHA's past experiences of communication with health care providers while seeking pain management is a stressful event that can influence an individual's current appraisal, coping choices, and perception of functional abilities.

In this chapter, the background of PLWHA's pain management experiences was introduced. The variables in the model, the purpose, research aims and research questions of the study were provided. This study was guided by Lazarus and Folkman's Stress, Appraisal and Coping model. The literature review in Chapter 2 addresses research results that are relevant to the understanding of the experiences of chronic pain in PLWHA and the factors that may influence those experiences that have been outlined in this chapter.

CHAPTER 2: LITERATURE REVIEW

INTRODUCTION

Following a brief review of HIV, this chapter presents a review of the literature concerning the component variables of the research model: past pain experiences, health care provider stigma related to pain management, past experiences with health care providers, current pain level, self-efficacy in communicating pain needs, pain management choices (self-care and/or seeking care activities), and confidence in performing life activities within the context of pain. Each section provides a summary of what is known and identifies the gaps in the literature where research is still needed.

HUMAN IMMUNODEFICIENCY VIRUS (HIV)

The human immunodeficiency virus (HIV) has been present worldwide since its recognition in 1981 afflicting more than 33.2 million people at the end of the year 2007 (UNAIDS *AIDS Epidemic Update)*. There are three main modes for HIV transmission (intravenous, childbirth, & sexually); however, HIV is primarily transmitted sexually in both heterosexual and homosexual populations worldwide (Mertens & Low-Beer, 1999). There are many risks factors for HIV infection; however, the most common risk factors include: multiple sex partners, history of sexually transmitted diseases (STDs), and frequency of unprotected sexual contact (Mertens & Low-Beer, 1999).

HIV has four stages which are based on clinical symptoms (WHO, 2006). The stages are: primary HIV infection, clinically asymptomatic, symptomatic HIV, and progression from HIV to acquired immune deficiency syndrome (AIDS) (WHO, 2006).

Due to advances in research throughout the past 20 years, medications known as highly active antiretroviral therapy (HAART) are used to manage HIV which has allowed PLWHA to live longer, although not necessarily healthier lives (Antiretroviral Therapy Cohort Collaboration, 2008; Siegel, et al., 2002). Programs throughout various medical fields have adapted to the changes in survival rates within this population (Gale & Pfalzer, 2008). PLWHA face many challenges while managing their chronic illness, not the least of which is stigma associated with the management of chronic pain often experienced as the illness progresses.

HIV and Health Care Provider Stigma

Stigma is a stressor that has been identified as a concept impacting the lives of PLWHA in many ways. For the purposes of this study, stigma is defined as "an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society," (Crowley & Guni, 2004, p.2). Alonzo and Reynolds (1995) described four phases of the stigma trajectory. First, "at risk: pre-stigma and the worried well; second, diagnosis: confronting an altered identity; third, latent: living between illness and health; and lastly, manifest: passage to social and physical death," (1995, p. 306). They identify that the perception of stigma is present and perceived at every stage of HIV.

Parker and Aggleton (2003) created a framework of stigma in order to understand the concept of HIV/AIDS-related stigma. The mode in which stigma is produced, reinforced, and repeated in society creates inequalities for people living with HIV/AIDS. This inequality begins first as a 'significantly discrediting attribute' stigma (Parker & Aggleton, 2003, p.13). Next, stigma develops into a social difference that is collectively strengthened and reproduced creating "inequalities of class, race, gender and sexuality,"

(2003, p.13). Parker and Aggleton suggest that HIV/AIDS-related stigma in communities (nationally and globally) can be minimized by performing both empirical and intervention research which when combined with advocacy, policy and legal elements has the best outcomes for prevention of HIV stigma. Examining the framework of stigma is important in order to begin to understand what PLWHA face when interacting with health care providers (HCPs) in an attempt to manage their chronic illness.

Berger, Ferrans and Lashley (2001) in a study with 318 HIV positive individuals, found that people living with HIV described their experiences with stigma as including concerns about disclosing their HIV status and with public attitudes toward people with HIV. However, they also identified that PLWHA expressed feelings of personalized stigma and negative self-image.

Furthermore, Crowley and Guni (2004) found that AIDS stigma affects health-seeking behavior, quality of health care received, HIV test-seeking behavior, disclosure of HIV status, and social support delivered to patients.

Summary

PLWHA experience stigma from a multitude of sources every day (self, community, national, and global). The literature suggests that one of the most damaging sources of stigma is from health care providers. Health care provider stigma can affect how PLWHA's manage their chronic illness (e.g. in partnership with/ or in spite of health care providers). Each time there is uncontrolled pain, the PLWHA reflects on how they were treated previously when seeking care from health care providers. The quality of these previous experiences may influence the choices PLWHA make in order to manage the current pain experience. Unfortunately, the available literature does little to explore

the relationships between perceived health care provider stigma and specific health outcomes in PLWHA.

For example, little research has been conducted to explore the influences health care provider stigma has on the management of pain symptoms in PLWHA. One way to conceptualize the relationship between health care provider stigma and PLWHA pain management is that health care provider stigma may influence the PLWHA's self-efficacy of communicating their pain symptoms to the health care provider. Decreasing communication self-efficacy may result in ineffective communication between the health care provider and the PLWHA and result in inadequate pain management. This study describes factors influencing PLWHA's perceptions of health care provider stigma and its influences on their self-efficacy in communicating pain needs to the health care provider.

HIV and Pain

In this study, pain is defined as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage," (International Association for the Study of Pain, 1994). In PLWHA, pain has been identified as a frequently occurring symptom that requires complex management strategies. Furthermore, symptoms of pain decrease PLWHA's ability to perform daily life activities.

McCarberg, Nicholson, Todd, Plamer and Penles (2008) through an online survey sent to diverse chronic pain patients, sought to determine the economic, psychological and physical impact pain produces in patients and to determine the unmet needs of patients taking opioids. 606 chronic pain patients responded to the survey, and of those, 359 had moderate to severe chronic pain. Patients reported that current pain levels

negatively impact their activities of daily living, which further impacts many aspects of their lives from personal relationships to mental health. Additionally, researchers found that patients used both non-pharmacologic (lifestyle changes and over-the-counter medications, 62%) and pharmacologic (prescription medications, 75%) treatments to manage their pain.

In an early study, McCormack, Li, Zarowny and Singer (1993) evaluated the prevalence, pain impact, treatments and effectiveness of those treatments in an outpatient infectious disease clinic with a large HIV-positive patient population. Of the patients surveyed, 82 of 148 (55%) patients reported pain and 60-70% of these patients reported their daily activities were significantly impaired due to uncontrolled pain. Pain treatment of any kind was not present in 40% of patients with complaints of pain. Of the patients who were receiving pain treatment, only 65% reported adequate pain relief. This study was one of the first to bring attention to the uncontrolled symptom of pain in PLWHA and was followed by a number of studies, the findings of which are presented next.

O'Neil and Sherrard (1993) in a clinical presentation of the various pain syndromes reported by HIV+ patients reviewed and identified various opportunistic infections, neoplasms, and other health problems that are typically associated with complaints of pain in PLWHA. The authors emphasized PLWHA who experience pain require prompt management and treatment of the underlying causes of pain through precise symptom assessment and use of pharmaceutical and non-pharmaceutical measures.

Singer et al. (1993), in order to describe the longitudinal effects of HIV on the human nervous system, reviewed and studied the patient charts of a group of 394 HIV positive men (191 at baseline; 126 at year one; 77 at year two) who reported painful symptoms during a 2 year period. The eight most common painful illnesses at all stages

of systemic HIV disease include: headaches, AZT-induced headaches, herpes simplex, herpes zoster, peripheral neuropathy, back pain, throat pain, and arthralgia. As expected, PLWHA with more advanced stages of HIV disease progression reported more painful symptoms than those with a less advanced stage of HIV. Higher depression scores, a greater frequency of pain symptoms, and increased disability were found in men with advanced disease as compared to those with less advanced stage HIV.

Focusing on the under treatment of pain, Breitbart et al. (1996) evaluated the adequacy of analgesic treatment of pain and the predictors of pain under treatment in 366 HIV positive outpatients. Breitbart et al. (1996) concluded that 226 of the 366 (62%) patients reported 'persistent or frequent' complaints of pain. Furthermore, 85% of those patients reporting frequent pain were found to have inadequate analgesic pain management via assessment using the Pain Management Index (PMI). Patients in three categories were at greatest risk for under treatment of their pain. The categories were women, less educated, or those who contracted HIV through injection drug use (IDU); each received inadequate analgesic management.

Unfortunately, eight years after the initial findings reported by Breitbart and colleagues (1996), researchers continued to find widespread under treatment of pain in PLWHA. Dobalian, Tsao and Duncan (2004) investigated the effects of pain in the use of HIV/AIDS outpatient services among a nationally representative sample of 2267 adults over a period of 6 months. Pain during the previous 4 weeks, was reported in 67% of participants. Outpatient services were utilized more often by participants experiencing more complaints of pain, those who had poorer HIV/AIDS management, and those who had Medicaid, Medicare, and private insurance. In addition, participants who were in AIDS classification, unemployed, IV drug using females, or without college degrees, reported the highest levels of pain.

Summary

The research findings reviewed above illustrate that it is known that people living with HIV/AIDS (PLWHA) commonly experience chronic pain as their disease progresses. While researchers have identified pain as a symptom that PLWHA experience, the literature does not present the individual viewpoints of the pain experience in PLWHA. The lack of knowledge about the individual's experience and the factors (beyond physiological) that contribute to or influence PLWHA's pain experience may be a contributing factor to the poor rate of adequate pain management reported by PLWHA. The next step in improving pain management in this complex population is to understand their experiences with pain and the factors that influence those experiences.

Past Experiences Communicating with Health Care Provider

With such diverse etiologies, the pain management choices that PLWHA select depend upon their assessment of the level of pain they experience, the cause of that pain, and the stigma associated with communicating their pain needs to their health care providers. These findings support this study's assumption that PLWHA who experience chronic pain will have past experiences of communicating their pain needs to the health care providers and will likely appraise their current pain experience in the context of those past experiences.

Moskowitz, et al (2011) explored whether clinicians' trust in marginalized HIV+ patients differed by race and ethnicity when clinicians were prescribing opioid analgesics due to concerns of misuse. Of 61 primary care providers, (78% Caucasian and 46% males), caring for 169 HIV+ participant, (65.1% male and 46.8% African-American, average age 50), using the physician trust in patients scale (PTPS), researchers found opioid analgesic misuse (as well as illicit drug use) was not statistically significant

between racial or ethnic groups, p= 0.71 and p= 0.18. Ethnicity was statistically significant with lower PTPS scores for non-white patients and lower PTPS scores for participants who are currently using illicit drugs. However, opioid analgesic misuse was not significantly associated with differences in PTPS scores. Health care providers reported less trust of patients who were of non-white race/ethnicity and who had an illicit drug use history which is consistent with other study findings. Trust is a subjective assessment and is an important part of the clinical visit, especially when an HIV+ patient is seeking medical care for chronic pain.

Additionally, in 2010, Vijayaraghavan, et al, sought to determine primary care providers (PCPs), accuracy of estimating both opioid analgesic misuse and illicit drug use in a 2 year longitudinal study of chronic non-cancer pain in 240 indigent HIV+ patients and their 90 PCPs. PCPs estimated that 49.5% of their patients had opioid analgesic misuse (altered the route, sold, or got high); however, when compared to patient self-report, PCPs were more likely to overestimate misuse, especially in African-American and younger patients.

In earlier work, Jensen, Turner and Romano (1991) explored the relationships between chronic pain coping strategies and life activities self-efficacy in 114 non-HIV patients with chronic pain. Participants reported their pain severity, health-related dysfunction, use of eight coping strategies, and outcome expectancies of the coping strategies. The eight coping strategies were: active exercise, stretching, rest, take narcotic medications, keep myself busy with something interesting, muscle strengthening exercises, ignore the pain, and active relaxation. Patients' beliefs about their capabilities were strongly correlated with coping activities chosen. Hierarchical multiple regression, controlling for pain severity, revealed that self-efficacy beliefs added a significant amount to the variance in coping activities chosen. The amount of additional variance

explained ranged from 10% (relaxation exercise) to 41% (opioid medication use), median = 26.5%.

Summary

From the studies presented in this section, it is apparent that most often, when patients experience chronic pain and seek medical care for treatment, there are interactions taking place between the clinician and the patient which are very complex. These studies revealed that HIV+ patients commonly experience stigma during the health care provider interaction. These negative interactions are frequent, and thus it can be assumed that PLWHA will likely experience difficult situations at some point when seeking care. Depending upon their ethnicity and previous substance abuse history, patients may not receive acceptable standards of care for symptom relief of chronic pain.

APPRAISAL OF COMMUNICATION SELF-EFFICACY

Another concept that is central to PLWHA's pain symptom management is the individual's cognitive appraisal of pain and his or her self-efficacy in communicating pain needs to the health care provider. Lazarus and Folkman define cognitive appraisal as "the process of categorizing an encounter, and its various facets, with respect to its significance for well being," (1984, p.31). According to the Stress, Appraisal and Coping model, there are "two basic forms of appraisal: primary appraisal (what is at stake for the person) and secondary appraisal (the person's evaluation of coping options)," (Lazarus & Folkman, 1984, p.315). Furthermore, cognitive appraisal is "the individual's subjective interpretation of a transaction," (Lazarus & Folkman, 1984, p.46). With this in mind, each time a PLWHA experiences pain, there is an individual subjective assessment made of that symptom's severity and threat to the individual and the individual's ability to

respond to that threat. PLWHA appraise the threat of pain symptoms in the context of their ability to relieve that pain.

Shively, Smith, Bormann and Gifford (2002) were one of the first groups of researchers to describe the measurement of self-efficacy in HIV for specific disease management behaviors through the HIV Self-Efficacy Questionnaire (HIV-SE). They conducted a study to evaluate the psychometric properties of the HIV-SE which consists of 34 items in 6 subscales: "Managing Depression/Mood, Managing and Adhering to Medications, Managing Symptoms, Communicating with Health Care Providers, Getting Support from Others, and Managing Fatigue," (Shively, et al, 2002, p.372). From previous research, these researchers believed that adults living with HIV would encounter these 6 domains during their disease management. In a cross-sectional study of 153 HIV+ adults, researchers found that participants had high self-efficacy scores for "Communicating with Health Care Providers" and "Managing Medications." Internal consistency reliability scores were also high; Cronbach's alpha was 0.96 and the subscales ranged from 0.88 to 0.97. They concluded that health care encounters and communication between patient and provider should build self-efficacy in patients for better health behaviors and symptom management.

The ability to relieve pain is, in part, dependent upon an individual's appraisal of his/her self worth and abilities. In one study, Evans, et al., (2003) focused on HIV+ patients' negative self-thoughts in response to the pain symptoms of peripheral neuropathy. Evans found significant positive correlations between pain intensity and negative self-statements ($r= 0.42$), negative social cognitions ($r= 0.42$), and self-blame ($r= 0.26$) at a $p< 0.003$. Additionally, they found significant positive correlations between life activities within the context of pain [pain interference] and negative self-statements ($r=0.54$), negative social cognitions ($r= 0.44$), and self-blame ($r= 0.35$) at a $p< 0.003$.

They further explored if negative self-statements were able to predict pain intensity and ability to perform daily activities within the context of pain. The variance in pain intensity was not predicted by negative self-statements or self-blame; however, 35% of the variance in ability to perform daily activities within the context of pain was explained by negative self-statements, negative social cognitions and self-blame. Lastly, PLWHA who regularly express feelings of self-recrimination and shame can report lower pain tolerance.

In another study, Stroud, et al., (2000) assessed 163 patients with chronic non-HIV related pain. Patients were seen to have decreased activity levels and pain management when they expressed negative self-thoughts. Although this study was conducted with a different population of patients, researchers concluded that negative self-thoughts impacted a patient's interpretation of pain, similar to the findings reported by Evans et al.

In addition to self worth, an individual's appraisal of his/her ability to perform a task is important in relieving pain. This appraisal of one's ability is often referred to as self-efficacy. Self-efficacy is defined as an individual's confidence in his or her ability to perform a task or accomplish an outcome (Bandura, 1986). Communication self-efficacy is the individual's confidence in his or her ability to communicate pain needs to health care providers. In PLWHA, communication self-efficacy is important because it influences the choices PLWHA make to manage their chronic pain and thus the resulting health outcomes.

Little is known about the self-efficacy PLWHA have when it comes to communicating their pain management needs to health care providers. Nor do we know much about the number of PLWHA who do <u>not</u> communicate their pain needs to their providers. However, one study conducted with chronic non-HIV pain patients offers

some insight into the numbers of patients who do not communicate their pain needs to their health care providers. Watkins, Wollan, et al, (2006) evaluated unmet pain management needs in chronic non-HIV pain patients who do not seek medical treatment for their symptoms. A population based random sample of individuals older than 30 years of age who had visited a local health care provider at least once within 3 years was surveyed. Over 3500 people responded. Of those responding, 2211 reported pain for more than 3 months and 497 of those had not informed their primary care physician of their pain. These 497 participants were termed "silent sufferers" by the authors. Young and/or male participants reported less pain than female or older participants. For the first time, a previously unidentified population of chronic pain sufferers, 1 in 5 participants in this study, was described. It is unknown how many PLWHA are "silent sufferers".

Summary

The research findings summarized above reveal that little is known about how PLWHA appraise their pain symptoms and their abilities to respond to that pain. Evans and colleagues (2003) found that negative self-thoughts contributed to poor pain management and lower pain tolerance levels in HIV positive patients. Similar findings were reported by Stroud and colleagues in chronic non-HIV pain patients. While these studies offer some insight, they do little to provide information about the personal experiences of PLWHA and how those experiences influence their experiences with pain.

Next, one study conducted by Watkins and colleagues (2006) provides some insight into the numbers of individuals in the non-HIV pain population who fail to report their pain symptoms to their health care providers. This speaks to the magnitude of the problem within the general population, yet it fails to explicate the issues that PLWHA may have in communicating their pain needs to their health care provider. This study

addresses a portion of this gap in the literature by describing the relationships between PLWHA's communication self-efficacy and the choices they make to manage (cope with) their pain.

COPING

Conceptually, coping is defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person," (Lazarus & Folkman, 1984, p.141). For PLWHA, appraisal of their historical stressors (past pain experiences, health care provider stigma related to pain management, and past experiences with health care provider), their self-efficacy in communicating pain needs to their health care provider and their current pain level, influences the available coping activities for managing pain. PLWHA may make pain management choices (self-care and/or seeking care activities) depending on their level of self-efficacy in communicating their pain needs to a health care provider and their current pain level. A literature search revealed few studies focused on describing how PLWHA manage their pain symptoms; however, literature is available describing management activities used by non-HIV patients experiencing chronic pain symptoms. Therefore, both the HIV and non-HIV chronic pain literature is reviewed.

Pain Management Choices: Self-Care Activities

Self-care activities are attempts made by PLWHA with chronic pain to manage their pain without seeking professional medical care. Examples of self-care activities include, but are not limited to, praying, taking a bath, reading or watching TV, taking medications prescribed for a previous condition, or using alcohol or illicit drugs.

It is difficult to directly assess the self-care activities used by individuals to manage their chronic pain. One landmark study conducted by Holzemer et al. (1998) examined strategies used by PLWHA who experience pain symptoms. In this study, researchers used a set of standardized instruments along with a semi-structured interview to describe three main variables: patient self-reports of pain, patient perceptions of nursing as it related to pain management, and pain management strategies used by 249 AIDS patients from three different care settings (home nursing care, skilled nursing facilities and hospitals). Holzemer and colleagues found that use of pain medication was the most frequent strategy reported by patients (78%). Only a few patients (5%) reported using non-pharmacologic strategies such as massage or other nursing interventions; however, patients also reported that when they used self-care activities, they were 75% effective in managing their pain. Some of the non-pharmacologic strategies reportedly used by this sample were: rest and relaxation (14%), massage (6%), exercise (13%), and doing nothing (18%). There was a surprising lack of use of non-pharmacologic nursing interventions to manage pain by this sample (e.g. heat pads/hot baths, meditation, positioning, exercise and other non-pharmacologic interventions). Holzemer concluded that further examination of self-care activities as pain management strategies in PLWHA and the impact of pain on functional status of PLWHA were needed.

Self-care activities for pain management were also researched in 111 women living with HIV/AIDS in 2000 by Passik, et al. In this study, 67.8% of female participants reported pain, and 24.1 % reported complaints of constant pain. Researchers asked participants about beliefs, attitudes and prevalence of drug-taking behaviors and addiction among their peers. 76% (n=84) believed that more than half utilized street drugs or alcohol for symptom control. Furthermore, 44% (n= 48) of participants reported using someone else's medication and 48.7% (n= 53) reported purchasing opioids without

a prescription. Current drug abuse in the sample included: 59.6% (n=65) reported using cocaine daily, 67% (n=73) used marijuana monthly and 58.7% (n=64) used heroin monthly. 60.3% of participants agreed that pain could be so severe that a person might use illicit drugs (street drugs like heroin) to get relief; 62.1% believed the same statement when using non-prescribed drugs to get relief. The use of self-care activities evaluated in this study was also examined in the current study through qualitative questions.

Pain Management Choices: Seeking Care from HCP

Seeking care from health care provider (HCP) is when the PLWHA with chronic pain attempts to manage their pain by seeking professional medical care. Examples of 'seek care' include, but are not limited to, visiting a Medical Doctor (MD), Doctor of Osteopathy (DO), Advanced Practice Nurse (APN) or Pain Specialist and pain management programs.

Robb et al. (2006) examined the effects of a cognitive-behavioral pain management program (PMP) for 13 cancer patients with chronic treatment-related pain. The study was developed as a feasibility study for patient interventions and used a pretest-posttest design. The pain management program used for the study was based on PMP guidelines published by the Pain Society. Participants were evaluated at baseline and one follow-up visit. The study interventions included relaxation, education, goal setting and exercise training. Positive outcomes reported from the study included improved participant coping with pain and improved anxiety and depression scores, However specific t-values were not provided. Post-test results showed that participants reported a significant improvement in coping with pain, anxiety and depression at a $p<$ 0.01. Results imply that patients with chronic cancer treatment-related pain are positively impacted through use of a cognitive-behavioral pain management program.

A common type of pain experienced by PLWHA is peripheral neuropathy. Nicholas, et al. (2007) explored the unhealthy behaviors that PLWHA utilize to manage the symptom of pain who reported experiencing peripheral neuropathy in a sample of 450 patients in 4 different countries. In this descriptive cross-sectional design study, the four most common unhealthy pain management choices used to alleviate peripheral neuropathy reported were: smoking cigarettes (n=139), drinking alcohol (n=81), marijuana use (n=67) and street drugs (n=30) using the Revised Sign and Symptom Checklist for PLWHA (SSC-HIVrev). However, researchers used a 20-item self-care activity checklist, and found patients who used unhealthy behaviors reported higher mean scores of neuropathy intensity than those who did not utilize unhealthy pain management choices. Researchers concluded that clinicians need to improve their assessment of substance abuse behavior. Additionally, patients need education about medications and self-management activities for their peripheral neuropathy. These two changes would promote a partnership between clinician and patient for better patient outcomes.

Later, in 2010, Nicholas, et al. continued examining the efficacy of symptom management in 228 PLWHA and peripheral neuropathy who engage in self-care activities. After assessing the frequency of use of 18 self-care activities, three main classifications were identified. The 3 classifications were: 1) interactive self-care (e.g., walking, taking a hot bath or not doing anything), 2) complementary medicine (e.g., taking vitamins, receiving acupuncture or massage), and 3) negative health items (e.g., street drugs, alcohol or smoking cigarettes). Nicholas, et al. concluded that an important facet in PLWHA's lives is self-care management for peripheral neuropathy. They recommend that nurses assess and educate patients about available self-care techniques that, when used in combination with medications and complementary care, can have beneficial results for PLWHA.

Summary

Holzemer and colleagues conducted a landmark study to explore the pain management activities used by PLWHA. This study identified several pharmacological and non-pharmacological methods used to relieve pain. However, it is only one study and the sample is quite small. Similarly, Robb and colleagues conducted a small study with non-HIV patients to explore the effectiveness of a pain management program to reduce chronic pain. While these findings are exciting and support the effectiveness of self-care and professional programs for reducing pain, these studies are quite small and leave much to be explored in the management of chronic pain. Additionally, these studies do not speak to the factors that influence an individual's choice to use self-care activities or to seek care from a health care provider to manage their pain. This study described some of the factors that influence PLWHA's choices for pain management.

CONFIDENCE IN PERFORMING LIFE ACTIVITIES WITHIN THE CONTEXT OF PAIN

Confidence in performing life activities within the context of pain is dependent upon how well the PLWHA are able to manage their pain either through self-care activities or seeking care from health care providers. Additionally, confidence in performing life activities may also be related to the PLWHA's self-efficacy in communicating their pain needs to their health care provider. As it has been stated in other areas of this review, there are limited studies available that have been conducted with PLWHA. Therefore, the literature reviewed here is from studies with chronic pain patients (non-HIV and HIV).

Asghari and Nicholas (2001) examined the relationship between confidence in performing life activities and pain management choices using the Pain Behavior Questionnaire (PBQ) in 145 non-HIV chronic pain patients four times over a nine-month

period. The findings exposed that the confidence of each participant in their ability to perform tasks despite their pain at baseline is predictive of total pain behavior (and avoidance behaviors) during the nine month study period. This also suggests that confidence in performing life activities determined pain management choices and disability from living with pain. In this study, researchers determined that higher pain self-efficacy beliefs reduced avoidance behaviors.

An individual's confidence in performing life activities within the context of pain is rarely assessed, which undermines a key component of self-efficacy (beliefs regarding one's capabilities). Furthermore, life activities self-efficacy beliefs in chronic pain populations should be assessed by both performance levels of particular activities and the person's confidence in his/her ability to perform activities despite his/her pain (Nicholas, 2007).

In earlier work, Jensen, Turner and Romano (1991) explored the relationships between chronic pain coping strategies and life activities self-efficacy in 114 non-HIV patients with chronic pain. Participants reported their pain severity, health-related dysfunction, use of eight coping strategies, and outcome expectancies of the coping strategies. The eight coping strategies were: active exercise, stretching, rest, take narcotic medications, keep myself busy with something interesting, muscle strengthening exercises, ignore the pain, and active relaxation. Patients' beliefs about their capabilities were strongly correlated with coping activities chosen. Hierarchical multiple regression, controlling for pain severity, revealed that self-efficacy beliefs added a significant amount to the variance in coping activities chosen. The amount of additional variance explained ranged from 10% (relaxation exercise) to 41% (opioid medication use), median = 26.5%.

One study conducted by Samwell, et al., (2006) examined the effects of helplessness, passive-pain coping strategies, depression, disability and fear of pain in 169 adult chronic pain sufferers (non-HIV). Participants attended a pain center and completed questionnaires and pain diaries. Patient pain level was significantly correlated with patient fear of pain ($r= 0.24$, $p< 0.01$) and helplessness ($r= 0.38$, $p< 0.01$). Passive pain coping strategies (worrying $r=0.17$; retreating $r=0.20$; and resting $r=0.21$) were significantly correlated with pain level ($p<0.05$).

Regression analyses found that after controlling for disability, helplessness explained an additional 6% of the variance in patient pain level. Fear of pain and passive pain coping strategies did not significantly add to the variance in the model. After controlling for depression, helplessness explained an additional 8% of the variance in disability [ability to perform daily activities within the context of pain]. Passive pain coping explained another 6% of the variance. However, fear of pain did not add to the variance in this model.

Arnstein et al. (1999) explored how patient self-efficacy mediated the relationship between pain intensity and pain related disability in non-HIV chronic pain patients. 126 non-depressed chronic pain patients from three different outpatient pain clinics completed questionnaires prior to an initial consultation with a pain specialist. It was found that self-efficacy was negatively correlated with pain intensity ($r=-0.46$, $p=.001$) and pain related disability ($r=-0.59$, $p=0.001$). Additionally, self-efficacy mediated the relationship between pain intensity and pain-related disability. Overall, pain intensity and self-efficacy explained 44% of the variance in pain related disability. The authors concluded that self-efficacy and pain intensity contributed to the progression of pain-related disability in non- HIV patients with chronic pain. Therefore, Arnstein and colleagues concluded that the chronic pain patients' lack of beliefs in their capabilities to manage

their pain and function in spite of their pain is a significant predictor of the degree of disability in this population.

Summary

In the research findings reviewed above, it is evident that life activity self-efficacy influences the chronic pain patient's (non-HIV and HIV) ability to perform life activities within the context of pain. Additionally, this research revealed several factors that influence an individual's life activity self-efficacy. For example, when individuals have high self-efficacy, there is a decrease in avoidance behaviors. However, passive pain coping (e.g., rest) was found to contribute to disability in a chronic pain sample. Additionally, low self-efficacy, pain intensity, and helplessness contributed to participant disability.

It is important to note that the studies reviewed above focused on how confidence in performing life activities influenced pain management choices; however, they do not explore how pain management choices influenced the individuals' confidence in performing their life activities. The present study attempts to describe the prospective relationship between pain management choices and the subsequent confidence in performing life activities. It is acknowledged that, if the PLWHA makes a pain management choice that increases his/her confidence in his/her life activities, that individual may, in turn, be more likely to make that management choice again.

CONCLUSIONS FROM LITERATURE

In the sections above, the concepts of health care provider stigma, HIV pain, self-efficacy in communicating pain needs to the health care provider, pain management choices (self-care and/or seeking care activities), and confidence in performing life

activities within the context of pain are important concepts in understanding PLWHA's pain experience. There is research describing and assessing each concept in chronic non-HIV pain patients; however, there is a lack of research describing these concepts in people living with HIV/AIDS (PLWHA). In addition, the relationships between the pain experience, pain management choices (self-care and/or seeking care activities) and confidence in performing life activities within the context of pain in PLWHA has not been examined. Lastly, it was necessary to explore the influence of health care provider stigma and past health care experiences of pain management on the choices PLWHA make to manage their pain.

Specifically, studies have failed to answer the questions that were evaluated in this study. Due to gaps in the literature related to how each concept interacts, it was necessary to describe the relationships between self-efficacy in communicating pain needs and pain management choices (self-care and/or seeking care activities) in PLWHA and relationships between pain management choices (self-care and/or seeking care activities) and confidence in performing life activities within the context of pain.

This chapter reviewed the literature related to the variables pertinent to the model and present study. The present study aimed to increase understanding of the pain management experiences in PLWHA who report chronic pain and to elucidate the factors that influence this experience. A cross-sectional descriptive correlational design along with open-ended questions to explore the relationships between variables in the model was applied in studying the range of issues concerning pain management in PLWHA. In the next chapter, details regarding the methods used to conduct this study are described.

CHAPTER 3: METHODS

INTRODUCTION

In this chapter, the methods used for this study are described. First, the rationale for using a mixed-method approach based on the Stress, Coping and Appraisal Model is presented. The remainder of the chapter focuses on a description of the research design, sample, and procedures used for the protection of human subjects, setting, instruments, procedures for data collection, and data analysis methods. Finally, a description of the results from a pilot study of the qualitative methods used in this dissertation is summarized.

MIXED METHODS

A mixed-method approach includes at least one qualitative method and one quantitative method (Greene, Caracelli, & Graham, 1989).The mixed-methods approach has become appropriate for studying complex phenomenon (Steckler, McLeroy, Goodman, Bird, & McCormick, 1992), since the many facets of a phenomenon may be linked and well appraised through different methods (Sandelowski, 2000). Pain management in PLWHA is an example of a complex phenomenon that fits well with a mixed-methods approach.

This study used quantitative surveys to elicit data for the primary questions. Narrative descriptions were elicited from participants to help capture the meaning of quantitative findings. Therefore, quantitative findings were the primary focus, with qualitative narratives serving as complementary to the quantitative findings. This complementary approach to study implementation is supported by Green, et al. (1989).

RESEARCH DESIGN

This study used a cross-sectional descriptive correlational design along with open-ended questions to explore the relationships between health care provider stigma, past health care experiences, self-efficacy in communicating pain needs to the health care provider, pain management choices (self-care and/or seeking care activities), and confidence in performing life activities in people living with HIV/AIDS (PLWHA) experiencing chronic pain.

Sites .

This project was conducted in Austin, Texas. Participants were recruited from AIDS Services of Austin, Project Transitions and the David Powell Community Care Clinic. All three agencies are located in Austin, Texas and together serve over 4,000 clients with HIV each year. Letters of support from the directors of each agency were obtained, granting the principal investigator (PI) permission to use each agency for recruitment, data collection and interviews. The PI has a history of working with these agencies and has successfully conducted previous studies at these sites with support of site staff.

SAMPLE

Inclusion Criteria

Adults ($\geq$ 21 years of age) living with HIV who were receiving services at one or more of the recruitment sites in the Austin, Texas area and who reported having chronic pain for a minimum of 3 months, were able to speak English and to freely consent to being in the study were invited to participate.

Sample Size

When determining the necessary sample size for the study, the number of variables within the conceptual model was considered (Polit & Hungler, 1999). This study explored four variables: self-efficacy in communicating pain needs to the health care provider, pain management choices (self-care activities and seeking care), and confidence in performing life activities within the context of pain. Following the rule of 20 to 30 subjects per variable, a midpoint target sample size of 100 participants was selected.

PROCEDURES

Recruitment

Recruitment for the study was conducted at three locations in Austin: AIDS Services of Austin, Project Transitions, and the David Powell Community Care Clinic. Flyers were posted at each facility, and providers were informed of the study inclusion criteria. Potential participants were given a flyer about the study by health care providers or social workers who work with people living with HIV/AIDS (PLWHA). Participants who wanted more information about the study followed instructions on the flyer and contacted the principal investigator by phone or email.

The principal investigator contacted all persons who responded to the flyer and determined eligibility, provided information regarding the purpose of the study, and obtained verbal consent to participate. Once verbal consent was given, the investigator scheduled an appointment to meet at one of the recruitment sites, and answered any questions participants had related to the study.

Data Collection

Once the cover letter, approved by the IRB, was read out loud to participants by the PI, the PI asked each participant if he or she preferred to fill out the questionnaire packet on their own or with the PI reading questions out loud to them. The questionnaire packet included demographic questions, the Coping Inventory for Pain in Persons Living with HIV/AIDS (PLWHA), the HIV Self-Efficacy Questionnaire (HIV-SE), and the Pain Self-Efficacy Questionnaire (PSEQ). There were 69 items total and it took the participants no more than 30 minutes to answer the questions.

After filling out the questionnaire, each participant was invited to answer a series of open-ended questions. The questions asked the participant to speak about their personal experiences of pain and the self-care activities used to manage their pain. This conversation was audio-recorded and transcribed at a later time. Each site provided a private room for the PI to use during data collection sessions. This provided a safe and comfortable area for data collection that was familiar to and convenient for the participants. Interviews lasted between 5 and 20 minutes.

INSTRUMENTS

1. Participant Demographics

An investigator-developed tool was used to assess participant demographics. A form was used to gather standard demographics (e.g. age, gender, ethnicity/ culture, education, occupation) and illness related demographics (list of symptoms, comorbidities, HIV diagnosis date, pain level, and use of highly-active antiretroviral therapy (HAART) and pain medication).

2. Human Immunodeficiency Virus Self-Efficacy Questionnaire (HIV-SE)

This instrument was used to measure self-efficacy in communicating pain needs with health care providers. The participant's self-efficacy in communicating pain needs with their health care providers was measured using a 4-item subscale ("Communicating with Health Care Provider") from the Human Immunodeficiency Virus Self-Efficacy Questionnaire (HIV-SE) (Shively, Gifford, Bormann, & Smith 1998).

The HIV-SE is a 34-item questionnaire that uses a 10-point Likert response scale. Respondents are asked to indicate how sure or confident they are to do a task at the present time, using a scale of 1 (not at all sure) to 10 (totally sure). Responses are summed, with higher scores indicating higher self-efficacy. There are 6 subscales examining various aspects of living with HIV/AIDS. The subscales are: managing mood, managing and adhering to medications, managing symptoms, communicating with health care provider, getting support/help and managing fatigue. The HIV-SE has been used in other studies with HIV participants and Cronbach's alpha for the entire 34-item questionnaire was .96, suggesting excellent internal consistency (Shively, et al., 2002). The alpha for this study was 0.94.

The subscale "Getting Support/Help" was used to measure specific activities to manage PLWHA's pain. The alpha for this 5-item subscale was 0.77 for this study.

The subscale "Communicating with Health Care Provider" was used to measure the PLWHA's communication self-efficacy when communicating pain needs to their health care provider (HCP). The alpha for this 4-item subscale was 0.74 for this study.

3. ***Coping Inventory for Persons Living with HIV/AIDS (PLWHA)***

This instrument was used to measure pain management choices (self-care and/or seeking care activities). The participants' use of specific activities to manage their pain

was measured using the Coping Inventory for Pain in Persons Living with HIV/AIDS and the 5-item "Getting Support/Help" subscale from the Human Immunodeficiency Virus Self-Efficacy Questionnaire (HIV-SE) (Shively, Gifford, Bormann, & Smith 1998).

The Coping Inventory for Pain in Persons Living with HIV/AIDS (PLWHA) is an investigator-developed 12-item questionnaire. Participants are asked to indicate their likelihood of using each of the activities listed to manage their pain on a 5-point Likert scale where 1=least likely to 5=most likely. The scores were summed for all self-care and seeking care activities. Higher scores showed greater likelihood for the individual to use each activity. The data were examined by category and for the unique contribution of each item. The alpha for this study was 0.39.

4. ***Pain Self-Efficacy Questionnaire (PSEQ)***

This instrument was used to measure the confidence in performing life activities within the context of pain. The participants' confidence in performing their life activities while experiencing chronic pain was measured using the Pain Self-Efficacy Questionnaire (PSEQ) (Asghari & Nicholas, 2001). The PSEQ is a 10-item questionnaire that measures an individual's ability to accomplish different life activities within the context of pain. Participants are asked to indicate on a 7-point Likert scale where 0=not at all confident to 6=completely confident, how confident they are in performing a series of activities within the context of their pain. Questions include the participant's ability to do hobbies, leisure activities and household chores despite experiencing pain. The questionnaire is scored by summing responses with higher scores equaling greater confidence in performing activities. The PSEQ has been used in studies with chronic pain populations and the Cronbach's alpha was .92, showing the questionnaire has strong internal consistency (Asghari & Nicholas, 2001). The alpha for this study was 0.90.

5. ***Open-ended Questions***

Open-ended questions were used to elicit narratives from participants about their experiences with pain management in one face-to-face interview. The interview was optional to participants, with a goal of 20% participation. The following questions were asked of all participants who indicated an interest in the interview portion of the study.

1. Tell me about your current pain level and its location.

    Sub-question: Rate your level of pain on a scale of 0 to 10 with 0 being no pain and 10 being the worst pain.

Now, reflecting on a specific pain experience in the past, please tell me…

2. How did you do manage your pain? Did it work?

    Sub-question: Did you ever use non-prescription or non-prescribed medications?

    Sub-question: Do you feel your pain isolated you from other people?

3. What barriers you experienced, if any, when seeking pain relief?

    Sub-question: Were health care providers helpful or were health care providers not helpful when you sought care for your pain?

    Sub-question: Do you feel people living with HIV/AIDS are treated differently by health care providers when seeking care to manage the symptom of pain? If so, tell me more.

4. What does managing your pain mean to you?

    Sub-question: Is there anything you would like health care providers to know regarding living with pain and seeking effective pain management?

ANALYSIS

Data Preparation

Questionnaires were reviewed for completeness and coded for data entry. The questionnaire data was entered into a computer database for scoring and analysis using SPSS Version 18 (SPSS Inc. Chicago, IL). Prior to any analysis, data was checked for accuracy and missing data and corrections were made as necessary.

Statistical Analysis

Descriptive statistics were performed on all participant demographic variables to describe the sample, frequencies and percentages for the categorical variables, means and standard deviations for continuous variables. Summary descriptive statistics were calculated on the following demographic characteristics:

Client background data (age, gender, race, education level)

Client illness history (symptoms, comorbidities, HIV diagnosis date)

Client medication history (HAART, pain medications)

Client Pain (type, location, duration)

Descriptive statistics (means and standard deviations) were calculated for participant communication of pain, pain management choices (self-care and/or seeking care activities) and confidence in performing life activities. Product-moment correlation coefficient was used to explore bivariate relationships between communication, pain management choices (self-care and/or seeking care activities), and confidence in performing life activities. Conclusions were made on the strength, significance, and direction of these relationships.

Qualitative data were used to inform interpretations of the relationships between communication self-efficacy, pain management choices (self-care and/or seeking care

activities), and confidence in performing life activities in people living with HIV/AIDS (PLWHA) who experience chronic pain.

More specifically, qualitative data were used to inform interpretations of the relationships between pain management choices (self-care and/or seeking care activities), influences of health care provider stigma and past health care experiences in people living with HIV/AIDS (PLWHA) who experience chronic pain. Results of qualitative analysis were used primarily to answer research questions 1 and 2; specific findings are reported in chapter 4.

Qualitative content analysis based on Miles and Huberman's (1994) recommendations for early stages of analysis was used to organize the collected narratives. The process begins with data reduction, which is when the researcher selects, simplifies and focuses on transforming the data from the transcripts and field notes (Miles & Huberman, 1994). It is a continuous process during analysis and includes writing summaries and memos, coding and making clusters. From data reduction, the data is organized in context which leads to the next step of data display. By using the data display, the information is assembled into a compact form such as a graph, chart or network (Miles & Huberman, 1994). The data display allows the researcher to create a chart, or matrix, detailing the data that have been chosen to be analyzed (Miles & Huberman, 1994). The final step is conclusion drawing and verification, which occurs throughout the whole process in a cyclical manner allowing the researcher to make preliminary conclusions. This step has the researcher utilize the data display to bring together the analytic text (Miles & Huberman, 1994). It is important to bring the analytic text and data display together in the conclusion to finalize the analysis with support.

Analysis of data was conducted in the following manner to address the specific research aims:

Aim 1) to describe PLWHA's self-efficacy in communicating their pain needs to healthcare providers, pain management choices (self-care and/or seeking care activities), and PLWHA's confidence in performing life activities within the context of pain,

RESEARCH QUESTION 1

How do PLWHA describe self-efficacy to communicate their pain needs to healthcare providers, pain management choices (self-care and/or seeking care activities), and PLWHA's confidence in performing life activities within the context of pain?

This question was answered by analyzing both the qualitative and quantitative data. Narratives were used to describe pain management choices used by PLWHA (interview question 2). Interview transcripts were analyzed using content analysis (procedure described above). The HIV-SE subscale "Communicating with Health Care Provider" scores were used to describe PLWHA's self-efficacy in communicating their pain needs. And, the Pain Self-Efficacy questionnaire (total) scores were used to describe the PLWHA's confidence in performing life activities within the context of pain.

Aim 2) to describe the influence of health care provider stigma and past health care experiences on the PLWHA's self-efficacy in communicating pain needs to the healthcare provider,

RESEARCH QUESTION 2

What are the influences of health care provider stigma and past health care experiences on PLWHA's self-efficacy to communicate pain needs?

This question was answered by analyzing both the qualitative and quantitative data. Interview transcripts were analyzed using content analysis. Narratives were used to explore descriptions of health care provider stigma and past experiences participants

reported with their health care provider while seeking care for pain (interview question 3). The HIV-SE subscale "Communicating with Health Care Provider" scores were used to describe PLWHA's self-efficacy in communicating their pain needs.

Aim 3) to explore the relationships between PLWHA's self-efficacy in communicating pain needs and their pain management choices (self-care and/or seeking care activities),

RESEARCH QUESTION 3

What are the relationships between self-efficacy to communicate pain needs and pain management choices (self-care and/or seeking care activities) in PLWHA?

This question was answered by analyzing the summary scores of the HIV-SE "Communicating with Health Care Provider" subscale and the Coping Inventory for Pain in Persons living with HIV/AIDS questionnaire using *Pearson's r*. Correlations were performed and conclusions were made on the strength, significance, and direction of these relationships. This question was also answered by analyzing the HIV-SE subscale "Getting Support/Help" summary scores and the "Communicating with Health Care Provider" subscale summary scores to measure specific activities to manage PLWHA's pain using *Pearson's r*. Correlations were performed and conclusions were made on the strength, significance, and direction of these relationships.

Aim 4) to explore the relationships between PLWHA's pain management choices (self-care and/or seeking care activities) and confidence in performing life activities within the context of pain.

RESEARCH QUESTION 4

What are the relationships between PLWHA's pain management choices (self-care and/or seeking care activities) and their confidence in performing life activities within the context of pain?

This question was answered by analyzing the relationship between summary scores of the Coping Inventory for Pain in Persons living with HIV/AIDS questionnaire and the Pain Self-Efficacy questionnaire (confidence in performing life activities) using Pearson's *r*. Correlations were performed and conclusions were made on the strength, significance, and direction of these relationships.

PROTECTION OF HUMAN SUBJECTS

Risk to Participants

The sample was 100 people living with HIV/AIDS (PLWHA) who self-identified as a person experiencing pain symptoms that had lasted more than 3 months. The participants were at least 21 years of age, cognitively intact and mostly ambulatory. Additionally, participants were considered to be a vulnerable population due to their HIV+ status, thus appropriate precautions were taken following human subject protection recommendations. Participants were receiving services at one or more of the three recruitment sites.

Sources of Material

Sources of research material were the data gathered by participant's self report for demographic questionnaire, and the instruments: HIV-SE, Coping Inventory for Pain in Persons Living with HIV/AIDS, PSEQ and interviews. Data were collected in an interview format with the principal investigator conducting all interviews in person.

Additional data was in the form of narratives to open-ended questions through field notes and audio recordings. No participant names were used in either note taking or audio recordings. Each participant was assigned a unique code number and the list linking code numbers to participant names were kept separately from data in a secured file accessible only to the principal investigator. No names of participants were used in the final report. All publications will exclude any information that will make it possible to identify any participant.

All data collected including audio files, transcriptions, field notes and demographic information was stored in a secure and locked file cabinet accessible to the PI only. Audio files had an assigned code number and not the participants' names.

Potential Risks

There were no foreseeable physical risks for participants in this study. If participants indicated a discomfort with answering any of the questions, they were reminded by the PI that they did not have to answer any questions that made them uncomfortable. No invasive procedures were included in the study, and the data obtained did not expose the participant to any social or legal risks. Loss of confidentiality would have been a potential risk if the enrollment log had been associated with data, but this did not occur. Confidentiality was protected by having the master list linking names to code numbers assigned to participants kept in a secure place and separate from the collected data accessible only by the principal investigator

Protection Against Risks

This study was approved by the Institutional Review Board at the University of Texas at Austin. Through the initial telephone conversation, the investigator determined

eligibility, provided information regarding the purpose of the study, explained procedures, and attained verbal consent to participate. Once verbal consent was given, the investigator scheduled an appointment in a convenient, safe and comfortable environment at each site to meet and each participant was read the cover letter by the PI, and then given a copy for their records. The cover letter was approved by the IRB and included information regarding the study and answered any questions related to the study.

Protection of Confidentiality

In this study, privacy of the participant was controlled by holding the data collection procedure in a location the participant found convenient, safe and comfortable at each site. The investigator was as flexible as possible with the location and scheduling of the data collection procedures for each participant.

Adverse Effects

As stated above, no major risks were anticipated to participants in this study. The principal investigator was trained in procedures that respect the rights of human subjects. The study protocol assumed PLWHA volunteering to participate had the cognitive capacity to consent and to participate in research. All participants appeared to have the cognitive capacity to understand the cover letter and the research protocol. No participants were excluded from participation because they appeared to not have the capacity to make informed consent.

POTENTIAL BENEFITS OF THIS PROJECT TO THE PARTICIPANTS AND OTHERS

Participants may have received some psychological benefit from discussing their individual experiences of attempting to manage symptoms of chronic pain as a PLWHA

with an interested and objective person. Each participant who completed the questionnaire packet received a $10.00 gift card to H-E-B as compensation for his/her participation in the study. There was no additional compensation for answering the open-ended questions.

IMPORTANCE OF THE KNOWLEDGE TO BE GAINED

Little is known about the experiences PLWHA have when attempting to manage the complex and chronic pain symptoms they experience as part of their daily life. Understanding the pain management experience from the individual perspective will help health care providers to understand the PLWHA's pain management needs as well as the barriers these patients experience when attempting to receive adequate pain management. This knowledge provides a baseline for continued research and investigation of symptoms experienced within the chronic illness of HIV and the barriers to care perceived by the PLWHA. The benefit to society from knowledge gained about the challenges faced by PLWHA in attempts to manage their chronic pain far outweighs the risks in this study.

PILOT STUDY

In this section, the purpose, setting and sampling process, procedures, data analysis and findings of the pilot study were described. Data from this study were used to develop the dissertation proposal in the identified population. Furthermore, this study assisted the investigator in testing the qualitative interview schedule and other study procedures.

Purpose

The purpose of this qualitative descriptive study was to elicit narratives regarding the self-care activities taken to manage the experience of pain in adults living with HIV to better understand patient pain experiences. Individuals were asked to describe the self-care activities taken when pain is experienced, barriers to pain management and what managing pain symptoms means to them. It is important to identify patient self-care activities and resources used to manage pain over time.

The specific aims were as follows:

1) To explore how adults living with HIV manage their pain.

2) To explore barriers adults living with HIV encounter when seeking pain management.

3) To explore the individual's perceptions of pain management and the impact of the pain experience on psychosocial and/or physical outcomes in patients living with HIV.

Research Design

This pilot study was a cross-sectional qualitative descriptive design used to elicit narratives regarding the self-care activities, barriers and the meaning of managing pain symptoms in adults living with HIV to better understand patient pain experiences. Individuals were asked to describe the self-care activities taken when pain is experienced, barriers to pain management and what managing pain symptoms means to them.

Setting and Sample

The site for this pilot study was Austin, Texas and the surrounding counties. The agencies involved in the research study included AIDS Services of Austin and Project

Transitions. Both agencies were located in Austin, Texas and served numerous HIV clients.

The sample for this study consisted of four adults, both men and women, living with HIV who were receiving services at one or more of the recruitment sites in the Austin, Texas area. Purposeful sampling was used in this qualitative descriptive study. This form of sampling has a main goal of gaining valuable cases considered information-rich (Sandelowski, 2000) sufficient to obtain descriptions of the pain experience and allow for testing of interview questions. The inclusion criteria for participants were the following: the individuals were 21 years of age or older, identified their HIV status and had experienced pain for at least 3 months.

Instruments

The participants were asked to respond to three open ended statements regarding the management of pain over no more than a 60 minute period of time. The three questions were: 1) please describe how you manage your pain, 2) please describe barriers you have experienced when seeking pain management, and 3) please describe what managing your pain means to you.

Procedures of the Pilot Study

Flyers were given to both recruitment sites to inform potential participants about the study. Potential participants contacted the PI via telephone or email. Recruitment through an initial telephone conversation, the investigator determined eligibility, and provided information regarding the purpose of the study, participant procedures and attained verbal consent to participate. Once verbal consent was given, the investigator scheduled an appointment to obtain written consent, and give the participant a form with

information regarding the study and answer any questions related to the study. In a convenient, safe and comfortable environment, each participant was asked to sign the consent form and was provided a copy for his/her records.

Data Collection

Participants were asked to respond to three open ended statements regarding the management of pain over no more than a 60 minute period of time. Participants were also asked to provide any additional information about their pain experiences that they feel may be of interest to the investigator and/or other HIV+ adults experiencing pain. The investigator gathered demographic information and took field notes throughout the interview. The interview was held in a convenient and comfortable environment for the participants.

Data Analysis

Qualitative data analysis was based on Miles and Huberman's (1994) process of content analysis. The researcher collected the data, had the interviews transcribed and assigned a particular color to each participant in order to easily identify which responses were from each participant. Using the color-coded transcripts, the researcher first created context charts for each participant, cutting quotes from the transcribed color-coded interviews then grouped the quotes together by research question. Next, the researcher created context charts for each research question, using the color-coded quotes from all participants that were grouped together by research question. From the context charts, the researcher then performed data reduction (coding) summarizing the data into labels and short phrases per research question. Subsequently, data display was used, creating conceptually clustered matrices of the labels and short phrases. Lastly, the researcher

reviewed the findings by meeting with an expert in qualitative data analysis to review the findings. The data display chosen was one main type of descriptive display called a conceptually clustered matrix. Building the display involved creating rows, eleven categories and four themes from the perspectives of the participants. *(See Table 3.1)* Data were entered into these rows by reviewing the transcript codes and relevant quotes.

Table3.1 Themes Outlined

Categories	Themes
Seek Medical Care	Strategies for Managing Pain
Perform Self-Management Activities	
Living Life	Making Meaning from Pain
Empowerment & Knowledge	
Listen to Body & Self-Worth	
Never Ending	Pain Basics
Stress & Fear	
Disability & Despair	Barriers for Trust
Health Care System	
HIV Decides	
Tolerance	

Findings of the Pilot Study

There were eleven categories assembled from the data analysis describing PLWHA's experiences of managing pain. These categories were then transformed into

four themes "Strategies for Managing Pain," "Making Meaning from Pain," "Pain Basics," and "Barriers for Trust."

Strategies for Managing Pain signifies activities of self care and use of resources to cope with the pain utilized by PLWHA. These include "seeking medical care, performing self-management activities, and living life." Each has been identified through responses from the participants. In response to pain, participants discussed the activities of exercise and movement that they do. Often, the participants discussed that taking pain medications was a first-line defense when managing their pain. In some cases, taking pain medications to manage the pain is a routine. However, participants reported the lack of desire to take narcotic medications due to the interference with their activities of daily living. Another participant who did not take narcotics explained her use of prayer and a few other activities when self-managing her pain. Additionally, a person who experiences pain might seek support from a nurse or case manager. The nurse or case manager can assist by providing resources within the local community, or in the client's neighborhood, in order for the individual to manage their pain. *(See Table 3.2.)*

Table 3.2 Strategies for Managing Pain

• Seek Medical Care
• Self-Management Activities - Prayer - Watch TV/Movies - Exercise - Get a massage - Develop a daily routine - Take previously prescribed medications - Take a bath - Do physical therapy - Use community resources - Meditation

Making Meaning from Pain signifies the desire for proper pain management in order to have quality of life. These include "empowerment and listening to one's body. One participant discussed the knowledge she had gained during her 13 years of living with HIV. She discussed with excitement the class she had taken at a local AIDS Service

Organization where there were other women who wanted to learn about their chronic illness where she became an advocate for other women who were new to the class. Participants made comments that reflected the importance of self-worth and the need to listen to their bodies during their involvement in their health and care. One participant stated her inner strength and her interest in continuing her life and being involved in her healthcare were manifestations of a desire to live life in a normal way.

Pain Basics signifies the physical pain experienced by PLWHA. There were three main categories that appeared from the interviews. These include "never ending, stress and fear, and disability and despair." Each participant described different types of pain symptoms, the locations of pain and their perceptions of that pain. Learning about the descriptions of pain and the perceptions from the participants suggests pain management is still a common problem within this population. Participants expressed their perceptions of their pain which included their emotions. The most common emotion expressed was stress, and each participant commented that as their levels of stress increased, so did their level of pain. Two participants revealed that at times, while coping with their chronic illness and pain, they have experienced disability and feelings of despair. One participant focused on her current pain symptoms in her knees which caused her to not have total control over her leg movements. The other participant stated that in her past, when seeking pain management, she had been told she may end up wheelchair-bound.

Barriers for Trust signifies the healthcare provider behaviors, interactions and system that were obstacles in proper pain management for PLWHA. Each participant

talked about the barriers they had experienced. There were four categories that illustrated their experiences. These include "health care provider behavior, health care system, HIV decides, and tolerance."

When participants sought care from health care providers, most of the interactions and behaviors of the health care providers they met with were negative. In most cases, there was no collaboration between the health care providers and the PLWHA. Health care provider behavior often lacked professionalism, which created frustration when PLWHA sought medical care.

As discussed in the previous section, the behaviors and interactions with health care providers are often negative, and PLWHA do not adequately get their needs met when seeking management of their pain. Moreover, just as these behaviors are negative, the health care system has limitations to properly care for this population. One participant discussed the limitations of her care because she could not afford private insurance. Due to the fact that she did not have private insurance, she had to wait for certain diagnostic studies and treatments for at least one month. This was frustrating and upsetting. Another participant described her frustration with the limitations the medication assistance programs placed on receiving medications. Although the medication assistance programs are very large and managed by the state, the programs are often complicated, and patients need information about their qualifications and benefits. This information often times comes from nurses or case managers; however, it is up to the individual to ask for this assistance.

Each participant revealed his/her awareness of the role of HIV within his/her body. Participants conveyed their awareness of the lack of control one has over HIV. For one participant, her awareness of HIV was very different; learning that she was HIV-positive was so overwhelming that she waited 6 years before seeking medical care. Two

participants were taking highly active anti-retroviral medications, but one participant was not. Her awareness of the lack of control HIV gives a person was expressed through her response thanking God that she did not yet need to take the HIV medications. Another different participant focused on the importance of knowing one's HIV-positive status, and once that is known, staying up-to-date with what their virus was doing.

Over the period of time that participants experienced pain, a tolerance for experiencing that pain developed. While one participant discussed her perceptions about tolerating pain, she expressed sadness in her tone of voice and often looked down at her hands. She also explained her high tolerance for pain and expressed grief for not focusing on her pain sooner.

SUMMARY OF PILOT STUDY

This study was the first step in constructing a conceptual framework and describing how PLWHA manage their pain, exploring barriers PLWHA encounter when seeking pain management, and exploring the individual's perceptions of pain management and the impact of the pain experience on psychosocial and/or physical outcomes in patients living with HIV. Qualitative description was used to analyze the data collected from four 60 minute interviews.

The four themes that emerged from the narratives of the study were "Strategies for Managing Pain," "Making Meaning from Pain," "Pain Basics" and "Barriers for Trust." The results of the pilot study assisted the PI in understanding pain self-management activities and pain self-care activities in order to inform the design of the dissertation. Additionally, the study demonstrated that the sample of interest was willing to share their experiences and that the staff and recruitment sites were in support of this

research. From the pilot study, the interview questions were revised for use in the dissertation study. The study supported performing a large study for the dissertation.

This chapter provided a summary of the methodology used to conduct this cross-sectional descriptive correlational design; using quantitative surveys to illicit data for the primary questions and narrative descriptions elicited from participants to help capture the meaning of quantitative findings. Therefore, quantitative findings were the primary focus, with qualitative narratives serving as complementary to the quantitative findings. Quantitative data for the current study were entered into a statistical program appropriate for the analysis of each of the stated research questions. Also discussed are the setting, sample size, recruitment methods, protection of human subjects, data analysis and rigor of the current study. Additionally, the results of the pilot study are reported. Results of the analyses are presented in Chapter 4.

CHAPTER 4: PRESENTATION OF FINDINGS

The purposes of this study were to increase understanding of the pain management experiences in PLWHA who report chronic pain and to elucidate the factors that influence this experience. To present the results of this study, this chapter describes the management of data, characteristics of the sample, descriptive statistics for the major study variables and the psychometric testing of instruments, and the findings related to each of the four research questions.

DATA MANAGEMENT

Missing Values

Data collection took place from October 6, 2010 to January 13, 2011. All data were collected in face-to-face interviews. There were no missing data.

Demographics

This sample of 100 persons living with HIV/AIDS (PLWHA) reported their race as 54% (n=54) African-American, 25% (n=25) Caucasian, and 21% (n=21) Hispanic. Sixty-six males and 34 females who ranged in age from 21 to 67 years with a mean age of 48.3 years (*SD* 8.26) participated in the study. The sample had a mean of 11.67 years of education. Additionally, 92% of the sample was not working, and 57% had quit their jobs due to illness. Within the sample, 84% were currently on highly active anti-retroviral therapy (HAART) regimens. See table 4.1 for a full description of the sample demographics.

Table 4.1 Characteristics of Sample (n=100)

Items		N	%	Mean	SD	Range
Age				48.31	8.26	21 - 67
Gender						
	Female	34	34			
	Male	66	66			
Race						
	African-American	54	54			
	Hispanic	21	21			
	Caucasian	25	25			
Education				11.67	2.38	3.0-20.0
Work Status						
	Working	8	8			
	Quit Work	92	92			
HAART						
	Yes	84	84			
	No	16	16			
Pain Medication						
	Yes	75	75			
	No	25	25			
Years living with HIV				12.89	6.51	1.0-26.0

Symptom Characteristics

Participants were asked to indicate which symptoms they experienced in the last month. These symptoms included: fatigue, confusion, pain, weight loss, difficulty breathing, nausea or vomiting, and diarrhea. The most frequently experienced symptom reported by participants was pain (96%). From the sample, 82% rated their pain at greater than or equal to 5 out of 10 on the 0 to 10 pain scale. Within the sample, 75% of participants were taking at least one prescribed opioid. Second to pain, 75% of participants had complaints of fatigue. The symptom of difficulty breathing was reported

in 34% of the participants. The least frequently identified symptoms were itching, sleeping, and blackouts. Two participants had symptoms of dental discomfort that they reported in the "Other" category. See Table 4.2 for a description of symptoms reported by participants.

Table 4.2 Symptom Characteristics (n=100)

Items	N
Fatigue	75
Confusion	42
Pain	96
Weight loss	45
Nausea/Vomiting	35
Difficulty Breathing	34
Diarrhea	47
Other	12

Descriptive Statistics and Instrument Psychometrics for Major Variables

Using the Lazarus and Folkman Stress, Appraisal and Coping model (1984) as the foundation for this study, three instruments were used to capture the experiences of PLWHA's with symptoms of chronic pain, their experiences with health care providers in communicating their pain needs, their strategies used to manage pain, and their perceptions of their abilities to perform daily activities in the context of their pain so that the relationships between these variables could be analyzed. Following are the descriptive statistics including the means, standard deviations, skewness, kurtosis and psychometric properties of the three major instruments: HIV Self-Efficacy Questionnaire, Coping Inventory for Pain in Persons with HIV/AIDS, and the Pain Self-Efficacy Questionnaire. A summary of the descriptive statistics is presented in Table 4.3.

Table 4.3 Descriptives and Psychometrics of Coping Inventory, HIVSE & PSEQ

			Skewness		Kurtosis		
	Range	Mean (*SD)*	Statistic	S.E.	Statistic	S.E.	α
HIV-SE	121 - 340	265.1 (44.67)	-.52	.24	.17	.48	.94
Coping	14 - 52	30.8 (6.42)	.18	.24	.87	.48	.39
PSEQ	4 - 60	36.8 (13.72)	-.34	.24	-.36	.48	.90

HIV Self-Efficacy Questionnaire

The HIV-SE is a 34-item questionnaire that uses a 10-point Likert response scale. Respondents are asked to indicate how sure or confident they are of performing a task at the present time, using a scale of 1 (not at all sure) to 10 (totally sure). Responses are summed, with higher scores indicating higher self-efficacy. The total mean score was 265.1 (*SD* 44.67) with a mean rating of 7.82 (*SD* 1.05) within the subscales, and a sample range of 5.75 to 9.52. For all statistical analyses, the HIV-SE and subscales were analyzed as interval data. For the subscale "Managing Depression," the mean rating score was 6.83 (*SD* 0.49), for the subscale "Managing Medications," the mean rating score was 8.99 (*SD* 0.28), for the subscale "Managing Symptoms," the mean rating was 7.58 (*SD* 0.37).

The subscale of interest for this study is the "Communicating with Health Care Provider" which has a mean rating score of 9.3 (*SD* 0.21) out of 10. Next, the "Getting Support/Help" subscale had a mean score of 7.66 (*SD* 0.74) out of 10. The final subscale "Managing Fatigue" had a mean score of 6.85 (*SD* 0.25) out of 10. Table 4.4 provides summary scores and psychometrics of each subscale.

Table 4.4 HIV Self-Efficacy Questionnaire (n=100)

Subscales	# of Items	Mean	SD	Cronbach α	Range
Managing Depression	9	6.83	0.49	0.938	5.7 - 7.2
Managing Medications	7	8.99	0.28	0.845	8.7 -9.5
Managing Symptoms	5	7.58	0.37	0.87	7.3 - 8.2
Communicate with HCP	4	9.39	0.21	0.739	9.1 - 9.6
Get Support/ Help	5	7.66	0.74	0.77	6.9 - 8.8
Managing Fatigue	4	6.85	0.25	0.903	6.6 - 7.2

The Cronbach's alpha for the sample was 0.936. The item-to-item correlation matrix was examined and there were no items creating redundancy. The item-total statistics for a calculated Cronbach's alpha ranged from 0.932 - 0.938, and deleting items did not calculate any new alpha stronger than the original alpha calculated with all 34 items.

Coping Inventory for Pain in Persons Living with HIV/AIDS

The Coping Inventory for Persons Living with HIV/AIDS is an investigator-developed 12-item questionnaire. Participants are asked to indicate their likelihood of using each of the activities listed to manage their pain on a 5-point Likert scale where 1 = "least likely" to 5 = "most likely". For all statistical analyses, the Coping Inventory for Persons Living with HIV/AIDS was analyzed as interval level data. The percentage of activities used was computed in scores greater than 3. The activities most likely to be performed by participants when experiencing pain were: tolerate the pain (82%), take a nap (71%), watch TV or movies (63%), exercise/walk (63%), and fear the pain (60%). The activities least likely to be performed by participants when experiencing pain were: drink alcohol (77%), visit physical therapist (70%), read a book or magazine (64%), get a

massage (49%), do nothing (46%), take a bath (41%), and exercise or walk (37%). The alpha for the questionnaire was 0.39. See Table 4.5 below for a full description of the coping pain choices reported by participants to manage their pain.

Table 4.5 Participant's Coping Strategies Used (Mean, SD, Percentage)

Coping Strategy	Mean	Std. Deviation	Percentage of Activities Used*
Take Bath	3.00	1.64	59
Do Nothing	2.71	1.65	51
Get Massage	2.53	1.57	49
Visit Physical Therapist	2.06	1.58	30
Read Book/ Magazine	2.28	1.56	36
Tolerate Pain	3.70	1.44	82
Drink Alcohol	1.65	1.17	23
Watch Movies/ TV	3.27	1.56	63
Take Nap	3.45	1.54	71
Exercise or Walk	3.06	1.50	63
Fear Pain	3.08	1.67	60

*Number of participants who rated activities used at level 3 or greater

Pain Self-Efficacy Questionnaire

For the 10-item, 7-point questionnaire, with 1 indicating "not at all confident" and 6 indicating "completely confident" a total score was calculated to indicate the level of each participant's pain self-efficacy. The total mean score for the PSEQ was 36.7 (*SD*

13.77), with a sample range of 4 to 60. For all statistical analyses, the PSEQ was analyzed as interval data. The percentage of confidence to perform was computed in scores greater than 3.

The Cronbach's alpha for this sample was 0.90. The item-to-item correlation matrix was examined and there were no items creating redundancy. See table 4.6 for the mean, standard deviation and confidence levels of each item.

Table 4.6 Confidence to Perform Life Activities within the Context of Pain

Life Activities within the Context of Pain	Mean	Std. Deviation	Confidence to Perform*
Enjoy things	3.9	1.77	81
Household chores	3.9	1.85	78
Socialize with friends & family	3.8	1.88	77
Cope with my pain	4.1	1.68	82
Some form of work	3.8	1.79	79
Activities & hobbies	3.8	1.75	79
Cope with my pain without medications	2.0	2.07	37
Accomplish my goals	3.6	1.98	72
Normal lifestyle	3.5	2.07	70
Become more active	3.5	1.89	73

*Number of participants who rated confidence level 3 or greater

Distribution of Scores

The data for the major variables of interest measured with the HIV Self-Efficacy, the Coping Inventory for Pain in Persons living with HIV/AIDS, and the Pain Self-Efficacy questionnaires were normally distributed. This was evidenced by histograms, stem and leaf plots and the acceptability of the skewness and kurtosis results.

ANALYSIS OF DATA

This section presents the findings for the four research questions that guided the inquiry to fulfill the aims of this research study which were to: 1) describe PLWHA's self-efficacy in communicating their pain needs to health care providers, pain management choices (self-care and/or seeking care activities), and PLWHA's confidence in performing life activities within the context of pain, 2) describe the influence of health care provider stigma and past health care experiences on the PLWHA's self-efficacy in communicating pain needs to the healthcare provider, 3) explore the relationships between PLWHA's self-efficacy in communicating pain needs and their pain management choices (self-care and/or seek care activities), and 4) to explore the relationships between PLWHA's pain management choices (self-care and/or seek care activities) and confidence in performing life activities within the context of pain. Descriptive statistics were used for the 4 research questions along with Pearson's correlations to examine the relationship between variables where appropriate.

Research Question #1:

How do PLWHA describe self-efficacy to communicate their pain needs to healthcare providers, pain management choices (self-care and/or seek care activities), and PLWHA's confidence in performing life activities within the context of pain?

The "Communicating with Health Care Provider" subscale of the HIV-SE was used to measure PLWHA self-efficacy in communicating their pain needs to health care providers. Participants reported a mean score of 9.3 (SD 0.20) out of a possible total score of 10. Overall, PLWHA rated their communication with their health care providers with high quantitative scores. Participants rated that they could ask about topics related to their illness that concerned them and that they could discuss openly with their health care

providers any problems that may be related to their medications. In addition, participants were able to work out differences with their health care providers when they arise and that participants could ask their health care providers topics about their medications and treatments that were of concern.

To describe PLWHA's pain management choices (self-care and/or seek care activities), the Coping Inventory for Pain in Persons living with HIV/AIDS was used (mean, SD, above presented/total score). In addition, narratives from the three open-ended questions were asked: "How did you manage your pain?", "Did you ever use non-prescription or non-prescribed medications?" and "Do you feel your pain isolated you from other people?" Interview transcripts were analyzed using content analysis.

Ninety-seven participants responded to the open-ended questions, and their responses to the first question varied widely. Many discussed using non-opioid, over-the-counter medications (e.g., ibuprofen and cigarettes) to heroin and morphine to manage their pain. Furthermore, most used a combination of activities such as applying heat, stretching, walking, and adjustments to activities of daily living along with taking medications that were either prescribed or not prescribed by their health care providers to manage their pain. Exemplar participant statements are given below for each question.

How did you manage your pain?

Participants described complex regimens to manage their pain. It is important to note that their first-line choice for managing their pain was not always resorting to prescribed or non-prescribed medications.

One participant stated, "I do a lot of different things. I like to walk. I walk a lot. And one of my nieces, she's a masseuse and she massages me. ..it helps. Eventually, it comes right back, but it relaxes me some. I tried over the counter [medications], and they

just didn't seem to work as good. Some of them did work--It helped some. Eventually, it really wasn't enough for the pain."

Another participant commented that she would walk as well as use a heating pad or soak in a hot tub to control her pain. She avoided taking "any kind of medication" since she did not want them to interfere with her antiretroviral medications (HAART). Another female shared that she used in combination with medications, "Heat, physical therapy, pain medication, and [I] tried to stay asleep. To relax, take some of the tension off."

Some participants discussed a routine to reduce pain and stress. One woman put it this way, "Yeah, I do a lot of activities around the house. Mostly in my most stressed part of it, I get up, I clean up, I cook. And you know I do a lot of stuff to keep me. Yeah, gardening and that. Keep me from being stressed." A 47-year old female described a more sedentary routine to manage her pain. "I start hurting; I'm just going to sit down. I'll take my medicine, um, you know, I already have patches on, so I can't put more patches on. And if I've already taken my medicine for the day, I can't take more. So I would just normally sit down and get myself comfortable, watch TV or something. Drink a cup of hot tea, green tea."

A male participant who arrived at the clinic using a walker, had been HIV+ for 10 years and took Morphine Sulfate and Neurontin for his newly diagnosed pain syndrome and neuropathy; he rated his pain at a 10/10 on the 0 to 10 scale. He stated, "[Pain] started a year, almost a year ago. I took a lot of ibuprofen and Tylenol. That doesn't work. Then they put me on a bunch of Tramadol and it didn't work. And then later on was prescribed Neurontin, and then, it went to Neurontin and Morphine. I use the Morphine every day."

One female who has been HIV+ for 15 years stated, "The older I got, the older I got, it [pain] got more different. I started getting pain because of my age. I'm 57 now." A different participant stated, "If I can control this pain, I would feel better altogether. That's a better feeling altogether. Give you more hope." Another added, "That would really be a blessing to have no pain at all. Yeah. It would be like heaven."

Did you ever use non-prescription or non-prescribed medications?

Again participants provided a wide variety of responses to this question. One participant spoke strongly about his desire to have health care professionals find better non-pharmacological solutions for pain management because he believed medications interfered with HAART. He described his self-care activities as including: "TENS unit, rocking massage chair, and visits to the Wright Wellness House for weekly acupuncture." Another stated, "No, I hate taking medicine."

Another individual commented on moving slowly to control the pain, "Yeah, because my friends and everybody who knows me, they know to back up. You know, they just…I can't get up. I can't, I move like a 100 year old man." While another participant said he used repositioning and physical therapy for pain control, "I was in physical therapy for a while. That didn't really work, but I still went through it to try, you know. And if I'm sitting, I lay down. If I'm lying down and it's hurting, then I get up. So it just depends on where I am."

One male, over age 40 who has been HIV+ for 16 years and rated his pain on the day of data collection at 9/10 on the 0 to 10 pain scale, stated he first managed his pain with alcohol, "I drank a lot. Liquor. Really what [anything] I could get my hands on, but the majority of it was liquor." At the time of the interview, he was prescribed Norco, Tramadol, Flexoril and Neurontin for his chronic pain, but stated, "Nothing takes my pain

away." He added, "And then some days I wake up, but there's always a constant ache there. A constant throbbing or something. There's something always going on there. I'm hurting always constantly."

Participants resorted to use of alcohol such as beer and liquor as well as street drugs like heroin, crack cocaine and marijuana for pain control. One participant stated that she did not use other people's medications to manage her pain, but preferred to smoke crack to manage her pain, "Street drugs helped me with pain and depression; they made me numb."

Others spoke of combining medications (prescribed and over-the-counter) to manage pain and side effects, "Between the three to four hours of the Norco, I try over-the-counter, uh, Aleve. Just so I don't have to have so much narcotics in my system all the time," stated one participant.

Another participant said, "I have muscle relaxants and I have hydrocortisone that I take. Only when I need it, Hydrocodone, I don't want to become addicted to it. I tolerate, uh, the pain as long as I can. And then when I just have to take them, I take them."

One transgender participant made this comment when discussing using someone else's (non-prescribed) medications, "Oh, no, you don't do that. No, no, no. My doctor don't play that. I talk to him, and he tell me whatever I need, he'll get it. If he can't prescribe it for me, then I don't need it." When asking another participant if non-prescribed medications were ever used, she replied, "I can't do that because of my HIV … I have to get, get the right medicine from my doctor. To tell me what medicine that doesn't interfere with my HIV medicine."

Do you feel your pain isolated you from other people?

Participants also described the isolation that they face while experiencing pain. One stated, "Because when I'm hurting real bad, I have a tendency to seclude myself. So nobody will touch me basically. I, um, then I'm not in the best of moods when I'm hurting real bad. So I don't want to lash out at anybody so I kind of seclude myself."

One 51-year old male said it this way, "I kept to myself. Go to my room and just tell everybody I don't feel well. I just want to rest. I don't want to be bugged. That's all. That's all, even though they catch on and check on me. They respect me enough to do that. Give me that wish."

Another participant discussed the isolation side effects of taking prescription medications. "Being able to function with the pain without being all drugged out. Most medications make you drowsy. Sometimes, I have to skip a dose just to cook dinner or go do what I need to do. You know, wait until once I'm in the house so I can take my medicine, so I'm not driving under the influence."

Isolation caused by pain impacts every aspect of PLWHA's lives. This comment from one female participant who has been HIV+ for 10 years, describes this phenomenon well, "I can't get out and go, you know, be sociable too much because I'm hurting. You don't want to be sociable and laugh and smile and talk to other people when you feel like crying. You don't want to even be seen. You don't even want to go grocery shopping. You just want to stay home, you know. When I'm in pain I don't want to go anywhere."

A male participant stated he felt isolated from his friends because of his use pot and cigarettes, "I usually sit outside and smoke cigarettes, and I stay shut in for like hours. And usually friends don't want to sit around and cigarette smoke. It would be boring with me sitting there being in pain or watch me in pain."

The Pain Self-efficacy questionnaire (PSEQ) was used to describe the PLWHA's confidence in performing life activities within the context of pain. Participants' scores ranged from 4 to 60. The mean score was 36.7 (SD 13.7). Only 37% of participants rated that they could cope with their pain without medications. This indicated that although participants rated most every item in the PSEQ with moderate confidence in performing life activities, it is difficult to use self-care activities only to manage their pain.

Research Question #2:

What are the influences of health care provider stigma and past health care experiences on PLWHA's self-efficacy to communicate pain needs to their healthcare providers?

This question was answered by analyzing both qualitative and quantitative data. Narratives were used to describe past pain experiences, health care provider stigma related to past pain management and past experiences with health care providers (interview question 3). Interview transcripts were analyzed using content analysis. The HIV-SE subscale "Communicating with Health Care Provider" was used to describe PLWHA's self-efficacy in communicating their pain needs.

As stated above, in research question 1, the "Communicating with Health Care Provider" subscale of the HIV-SE was used to measure PLWHA self-efficacy in communicating their pain needs to health care providers. Participants reported a mean score of 9.3 (SD 0.20) out of a possible total score of 10. Overall, PLWHA rated their communication with their health care providers with high quantitative scores. One additional item in the "Managing Symptoms" subscale of the HIV-SE asked participants, "How sure are you that you can keep the physical discomfort or pain of your disease from

interfering with the things you want to do?" The participant mean score on this item was 7.28 (SD 2.56) out of 10.

To understand the quantitative scores, there are responses from participants when answering the interview questions, "What barriers you experienced, if any, when seeking pain relief?", "Were health care providers helpful or were health care providers not helpful when you sought care for your pain?" and "Do you feel people living with HIV/AIDS are treated differently by health care providers when seeking care to manage the symptom of pain?" Ninety-seven participants responded to the open-ended questions, and their responses to the first question varied widely.

What barriers you experienced, if any, when seeking pain relief?

Negative experiences have occurred when these participants sought care for pain relief. One participant described his first experience with seeking care for pain relief, "When I first found out I was HIV+, I was at the [facility name]. And then people put me in a little room like this, and I was sitting there waiting for the doctor and everything. The doctor came in and said, "How long have you been HIV+?" and he walked out. He didn't give the chance to answer or anything. And then in a few minutes, he and this nurse and they're talking about you need to make an appointment at [facility name]. We'll send your paperwork over there."

One female participant described her negative interaction when going to the Emergency room for care. "The only barriers I've had was initially … because they put me on crutches. And immediately no one was paying attention when I kept telling them the crutches were aggravating my shoulder. It was hurting it worse. I had been on crutches before, and they kept telling me, "Well, you just have to get used to them. Put a

towel under your arm," …they wanted to do what they wanted to do and send me on my way."

One participant shared, "They [clinicians] need to listen more. They need to listen more and take in stride what the patient is saying to them because everybody's not the same. Everybody doesn't deal with their pain. There are some of us that have a high threshold as far as pain goes. And there are some that have no threshold when it comes to pain and everything and stuff. I think it would probably be more or less on a level where they need to spend time getting to know their patients so they would know how to handle the situation."

Underfunded patients also shared difficult experiences when seeking care, "It was a very bad experience. I'll never forget it. I don't think anyone should ever be treated like that, especially someone who is supposed to be caring for you and stuff. But that was very, very rude and I tell everybody about them over there at the [facility name]. You know because I don't, just because I don't have no money don't mean that I don't deserve healthcare. If I had the money, damn right I'd pay it. But I ain't got the money, but I'm sick and I need some help. And if you don't help me, I'm going to die."

Lack of access to specialized care also was a barrier when seeking pain relief. One participant stated, "..In 2009..That's when I got a PCP doctor. But it was a nurse practitioner, is what it was. He was the only [one] I could see because they were all scared of my HIV. I live in a little town."

Additionally, when asked about barriers to seeking care, one participant, reported a more positive experience, he stated, "Sure, they will [help]. They were always helpful. Always. Very considerate, yeah, very much so." About health care providers, the same participants said, "All the people I have been around and I've talked to. They seem to be pretty well equipped with the knowledge of what's needed. They seem real concerned

about it. So I'm pretty sure they're doing everything they can think of. So I think they're pretty well up on top of it. Just keep hanging with us and see what happens. Hope for the best." Whereas another participant reported, "I haven't experienced that [barriers to receiving care]. That's all I could say to that. I haven't experienced that."

Were health care providers helpful or were health care providers not helpful when you sought care for your pain?

One participant when facing difficult situations with health care providers commented, "I don't give no room for that. I ask questions and I expect answers. I know they got the answers so I keep on until I get the answer that I want. I pursue it. You know, I persist in it. I keep on, understand when I say this and then don't say no more. They're not even comprehending it. But I don't. I know myself better than they know me. So I live with myself. So I know what's happening to my body more than they know. So I just tell. That's all I do. Like I say I need to know. They know, professionally know, but I know physically and mentally because it's me. Yeah."

One participant stated, "Yeah because my doctor kind of shied away from the pain area. But too much, I have been in the hospital and seeing a neurologist. He's now convinced that I have to be on the pain meds, medication. I was like very upset. I was angry and I wanted to, I wanted to tell my doctor off. It just feels very, it makes you sad, and it makes you hurt and makes you think they don't care. You just, I think you might as well go ahead and die because they don't care."

A male participant related an interaction he had with a nurse when his T-cell count was very low, requiring contact isolation. He stated, "Well I had an incident when I was at [facility name] to where the nurse walked in. She had just got on shift. And they had me in a room, I was isolated so I wouldn't catch nothing from anybody else because

my T cells were so low. And this lady walked in and said, “Uh-uh I’m not taking care of him.” And she said it in front of me. She turned around. I got a six month old baby. My baby can’t get it and she walked out. It was really bad, it was really hard on me. Because not only do I have to deal with my sickness, I’m having to deal with people. They’re not going to take care of me because of my AIDS because they don’t have the education or they don’t want to get the education.”

For a female participant, she described her feelings when communicating with her health care provider, “I wouldn’t have any problem telling a doctor or whoever’s taking care of me how I feel about this pain. I have no problem explaining to them what I go through at night when I have it. You know what I’m saying? And to find out, and I really want them to find out what really causes it. If it’s not the HIV, then what is it?”

Participants also described positive experiences when seeking care. An example was stated by one participant, “Yeah they’re pretty much helpful. I got a good doctor. He suggested physical therapy and I didn’t know anything about it. It seems, I’d seen the doctor, the physical therapist, the first time the other day and it seems to be something that I’d like to try. I get free massages. It’s at the physical therapist.”

One African-American female participant said it this way, “Very helpful by telling me what things I can do without taking medications or what things I can do while I’m taking medications also that helps. Like taking a walk, bath or putting a warm towel over my legs, my knees.”

A 57-year old female described her interaction with her health care provider, “She [her doctor] just said I’m going to give you these pills. Try this at bedtime.” At her next visit the health care provider asked her when she was taking her medications for pain and, she informed her provider that, “..[she was] not taking them. I’m only taking a PRN when I get the pain. I’m going to take them. ‘No you need to take them every day, every night.’

[said her provider]. I didn't think I needed to take them, only take them for the pain. But she said no. I need to take them every night because I need to get enough in my system to work."

One participant who was no longer able to walk due to a severe pain syndrome stated, "They were helpful. Um, they were just nice and, uh, they always baby me. I like that. It's very supportive and very nice and very sweet. They always make sure to check my blood pressure and everything," to describe his health care provider interactions.

Additionally, a participant stated, "Yes, they've been helpful. And they're always trying to give me something or go through certain procedures to try to relieve the pain. Sometimes what they suggest works, and sometimes it doesn't, or it works for a little while and stops, you know. But every now and then I do get a little relief but never completely without pain."

Another participant shared, "Now that I'm on the pain medicines, it means a lot. And I'm very grateful that my doctor continues that every month. Yeah, I mean my spirits are a little bit better. I mean, sometimes, I'm down in the dumps, depressed sometimes."

Do you feel people living with HIV/AIDS are treated differently by health care providers when seeking care to manage the symptom of pain?

Participants described both positive and negative interactions with health care providers when seeking care for their symptom of pain.

Positive statements usually described incidents when the individual did not experience problems. One participant briefly stated, "I haven't experienced that. That's all I could say to that. I haven't experienced that."

One male stated, “Well my doctor and his nurses, they are really cool. And I can’t even tell them my little toe hurts without them helping me. Because they don’t like to hear anybody whine. They know I will whine even though I’m no big fusser, but sometimes I have to get on them and make them pay attention. But they’re always empathetic.”

Each participant had a unique way of describing his/her health care interactions when seeking care for pain. Here, one participant states, “I don’t think so. No, I mean if they’re a good, a good person, I don’t think, no. I haven’t seen anybody treat me differently. Maybe that’s because I don’t look for it. I don’t think I am different.”

Negative experiences were also described by participants when they sought care for their complaint of pain. One participant stated, “I was like very upset. I was angry and I wanted to, I wanted to tell my doctor off. It just feels very, it makes you sad and it makes you hurt and makes you think they don’t care. You just, I think you might as well go ahead and die because they don’t care.”

Another participant described his experience when he first sought care for pain. “The line, the difference between someone coming in and asking for medication that’s going to abuse it and the difference of the people that, that, you know, you really need it. Because I had a hard time when I first moved here. I mean I’d go to [facility name] and they’d tell me you ain’t getting nothing here. I mean I’m in pain, I’m on a walker. When I get down, I’m on a walker. I mean so and they were looking at me and talking to me like I was some pill fiend or something. Like I had done something. I was like hold up, wait a minute. I finally got mad and left. I said I ain’t never coming back to this hospital.”

With these experiences in mind, it is evident some PLWHA have experienced both negative and positive experiences with health care providers.

Research Question #3:

What are the relationships between PLWHA's self-efficacy to communicate pain needs to healthcare providers and their pain management choices (self-care and/or seek care activities)?

The "Communicating with Health Care Provider" subscale of the HIV-SE was used to measure PLWHA self-efficacy in communicating their pain needs to health care providers. Participants reported a mean score of 9.3 (SD 0.20) out of a possible total score of 10. The Coping Inventory for Pain in Persons Living with HIV/AIDS was used to assess the type and number of pain management choices (self-care and/or seek care activities) participants used to cope with their symptom of pain. Participants reported a mean score of 30.82 (SD 6.41) for total coping scores. Relationships between participant's self-efficacy in communicating their pain needs to health care providers and their pain management choices was explored using Pearson's *r*. The summary scores of the HIV-SE "Communicating with Health Care Provider" subscale and the Coping Inventory for Pain in Persons living with HIV/AIDS questionnaire were used for the analysis. A positive correlation (r= 0.462) was found although it was not statistically significant (p=.74). Additionally, the "Getting Support/Help" 5-item subscale from the HIV-SE was used to measure specific activities PLWHA used to manage their pain. Participants reported a mean score of 7.66 (SD 0.73) out of a possible score of 10. The summary scores of the HIV-SE "Communicating with Health Care Provider" subscale and summary scores of the "Getting Support/Help" subscale were used for the analysis. A significant positive correlation (r= 0.353, p= 0.05) was found.

Research Question #4:

What are the relationships between PLWHA's pain management choices (self-care and/or seek care activities) and their confidence in performing life activities within the context of pain?

The Coping Inventory for Pain in Persons Living with HIV/AIDS was used to assess the type and number of pain management choices participants used to cope with their symptom of pain. Participants reported a mean score of 30.82 (SD 6.41) for total coping scores. The Pain Self-Efficacy questionnaire (PSEQ) was used to assess participant's confidence in performing life activities within the context of pain. Participants reported a mean score of 36.78 (SD 13.72).

The relationship between participant's pain management choices and their confidence in performing life activities within the context of pain was explored using Pearson's *r*. The summary scores of the Coping Inventory for Pain in Persons Living with HIV/AIDS questionnaire and the Pain Self-Efficacy questionnaire were used for the analysis A significant positive correlation (r= 0.344, p=0.05) was found.

SUMMARY

In this chapter, findings of the study were presented by research question. Research question 1 utilized both qualitative (interview question 2) and quantitative data (HIV-SE communication subscale, Coping Inventory for Pain in Persons Living with HIV/AIDS and PSEQ total) to describe PLWHA self-efficacy in communicating their pain needs to health care providers, pain management choices (self-care and/or seeking care activities) and PLWHA confidence in performing life activities within the context of pain. Research question 2 also utilized both qualitative (Interview question 3) and

quantitative data (HIV-SE communication subscale and 1 item from the "Managing Symptoms" subscale) to describe the influence of health care provider stigma and past health care experiences on the PLWHA self-efficacy in communicating pain needs to the health care provider. Research question 3 was answered using the HIV-SE communication subscale, the Coping Inventory for Pain in Persons Living with HIV/AIDS and the "Getting Support/Help" HIV-SE subscale to explore the relationships between PLWHA self-efficacy in communicating pain needs and their pain management choices (self-care and/or seeking care activities). Lastly, research question 4 was answered by using the PSEQ total scores and the Coping Inventory for Pain in Persons Living with HIV/AIDS total scores to explore the relationships between PLWHA pain management choices (self-care and/or seeking care activities) and confidence in performing life activities within the context of pain. Chapter 5 will discuss in depth the conclusions of the data presented in this chapter.

CHAPTER 5: DISCUSSION AND RECOMMENDATIONS

This chapter discusses the study findings, assesses the strengths and limitations of the study and presents implications of the findings for future education, research and nursing practice. Discussion of the study findings will be presented in four sections reflecting the main variables of interest in the model. First, stressors (historical stressors) and how these influence PLWHA including past pain experiences, health care provider stigma related to pain management and past experiences with health care providers is discussed. Second, the PLWHA appraisal of historical stressors and their current pain level and self-efficacy in communicating their pain needs is presented. Third, the coping activities of pain management choices, both self-care and seeking care from health care providers are presented. Lastly, the concept of outcomes and the PLWHA's confidence in performing life activities within the context of pain is discussed.

Today, HIV medications triumph over many infections and disorders that once caused physical distress in PLWHA; however, the rate of pain complaints is rising in this population. The most common HIV-related pain is neuropathy, nerve damage to feet and hands causing constant numbness, burning, and/or tingling. Pain weakens the body and is a form of physical crisis. Everything from the immune system, to organs, to a person's functional status, and moods are negatively affected by chronic pain. Some people in this population become so uncomfortable that they are unable to function or move, resulting in further isolation. In this sample, due to the constant nature of their pain, participants devoted a considerable amount of time to managing their pain.

The sample recruited for this study was reflective of the Austin-area HIV/AIDS population who experience chronic pain. One hundred PLWHA participated in the study;

53% African-American, 21% Hispanic and 25% Caucasian. They were primarily male (66%), reported a mean age of 48 years and a mean of 13 years living with HIV.

STRESSORS (HISTORICAL STRESSORS, PAST EXPERIENCES AND STIGMA) THAT INFLUENCE PLWHA

The participants in this study experienced not only the physical trauma of constant pain, but also an additional level of stress and adversity when they sought care from health care professionals; the stigma of chronic pain.

Stigma is a stressor that has been identified as a concept impacting the lives of PLWHA in many ways. For the purposes of this study, stigma was defined as "an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society," (Crowley & Guni, 2004, p. 2). PLWHA often experience stigma when seeking care for chronic pain from health care providers. They may be labeled as 'drug seeking' or non-compliant by the health care providers, when in fact, they are continuing to request assistance for managing their pain because the pain has not been relieved or even lessened. People with chronic unrelenting pain live in fear of their pain. Add to this fear, the stigma they face when trying to seek care for that pain, and the person in pain has a life in daily crisis, stress, and anxiety.

PLWHA experience and respond to the symptom of pain on a daily basis. Many factors can influence the way PLWHA experience and respond to the symptom of pain. Because of the pervasive lack of adequate pain management by health care providers, PLWHA often resort to self-care activities to control their pain. Additionally, some health care providers recommend self-care activities for managing the symptom of pain. Chronic pain has been linked to decreased activities of daily living within the context of pain. Often, pain in PLWHA is multi-factorial, and this study sought to investigate the

impact of chronic pain on the life activities within the context of pain in the Austin-area adult HIV/AIDS population.

The current study found chronic pain management continues to be a problem in PLWHA. Participants shared their past experiences with health care providers which ranged from positive to neutral to negative when seeking medical care for pain. One participant, when asked about barriers to seeking care, reported a more positive experience, he stated, "Sure, they will [help]. They were always helpful. Always. Very considerate, yeah, very much so." About health care providers, the same participants said, "All the people I have been around and I've talked to. They seem to be pretty well equipped with the knowledge of what's needed. They seem real concerned about it. So I'm pretty sure they're doing everything they can think of. So I think they're pretty well up on top of it. Just keep hanging with us and see what happens. Hope for the best." Whereas another participant reported, "I haven't experienced that [barriers to receiving care]. That's all I could say to that. I haven't experienced that."

On the other hand, one female participant described her negative interaction when going to the Emergency room for care. "The only barriers I've had was initially … because they put me on crutches. And immediately no one was paying attention when I kept telling them the crutches were aggravating my shoulder. It was hurting it worse. I had been on crutches before, and they kept telling me, "Well, you just have to get used to them. Put a towel under your arm," …they wanted to do what they wanted to do and send me on my way."

These diverse experiences that participants reported ranged from making no difference in their long term care or self-efficacy to experiences with health care providers which had life changing negative effects, especially when encountering clinicians at non-HIV specialized clinics. One participant stated, "..In 2009..That's when

I got a PCP doctor. But it was a nurse practitioner, is what it was. He was the only [one] I could see because they were all scared of my HIV. I live in a little town." The literature presented in chapter 2 addresses the assorted issues of stigma and adversity that this population faces when seeking care to manage their chronic pain.

The participants in this study were a mean age of 48 years, had lived with HIV for a mean of 13 years, and reported a number of pain issues seen with advanced illness. The findings in this study through the interview questions were similar to what was reported by researchers in quantitative studies over 20 years ago. It is clear that historical stressors, past experiences with health care providers and stigma continue to negatively impact the PLWHA today.

In one of the first studies with PLWHA, conducted by Alonzo and Reynolds (1995) established that PLWHA will experience stigma at every stage of their illness. Participants in this study continued to report these experiences 16 years later. Furthermore, in another study, Singer, et al. (1993) found that common causes of long-term pain in PLWHA include migraines, bone pain, heartburn, muscle spasms, abdominal pain, arthralgias, and shingles. Researchers identified that pain symptoms occurred at all stages of the disease, but most commonly in the more advanced stages of HIV/AIDS.

In this study, the participants' reports of chronic unrelenting pain that was poorly managed by health care providers support this finding. McCarberg, et al. (2008) conducted a study in a non-HIV, severe chronic pain population of 359 and found that current levels of pain negatively impacted their activities of daily living and personal relationships. The current study assessed the variable "confidence in performing life activities within the context of pain" and found similar results in the Austin-area HIV/AIDS chronic pain population. Lastly, Breitbart, et al. in 1996 assessed an HIV+ sample size of 226 who reported 'persistent or frequent' pain and after evaluation,

researchers found that 85% were receiving inadequate analgesic therapy. They found that HIV+ persons reported under treatment of pain more commonly than non-HIV chronic pain patients.

The current study findings indicate a need for healthcare providers to move beyond quantitative measures for this complex problem. Patient-centered care and strong assessment with good communication from health care providers is essential when delivering care to this population who experience the complex symptom of pain.

APPRAISAL OF CURRENT PAIN LEVEL AND SELF-EFFICACY IN COMMUNICATING PAIN NEEDS

Most of the current study's participants rated their pain at consistently moderate to high levels on the 0 to 10 pain scale. Within the total sample, 75% were taking some form of prescribed medication to manage their symptom of pain from their health care providers. Medications ranged from naproxen or neurontin to hydrocodone or extended release morphine. However, most participants did not consider their pain symptoms to be well-controlled during the qualitative interviews. It is understood that pain may not completely cease in the chronic pain population, but the goal is to reduce the pain to a level that is acceptable to the patient, by following the WHO analgesic pain ladder. In this study, participants reported for the one item "keep the physical discomfort or pain of [their] disease from interfering with the things [they] want to do" an item mean score of 8.21 (*SD* 2.25) within the HIV-SE subscale of "Managing Symptoms;" the subscale mean was 7.28 (*SD* 2.56) out of a possible score of 10. This information differed when participants reported how they managed their pain and if their coping pain choices were effective or not.

One male, over age 40 who has been HIV+ for 16 years and rated his pain on the day of data collection at 9/10 on the 0 to 10 pain scale, stated he first managed his pain with alcohol, "I drank a lot. Liquor. Really what [anything] I could get my hands on, but the majority of it was liquor." At the time of the interview, he was prescribed Norco, Tramadol, Flexoril and Neurontin for his chronic pain, but stated, "Nothing takes my pain away." He added, "And then some days I wake up, but there's always a constant ache there. A constant throbbing or something. There's something always going on there. I'm hurting always constantly."

Another male participant who arrived at the clinic using a walker, had been HIV+ for 10 years and took Morphine Sulfate and Neurontin for his newly diagnosed pain syndrome and neuropathy; he rated his pain at a 10/10 on the 0 to 10 scale. He stated, "[Pain] started a year, almost a year ago. I took a lot of ibuprofen and Tylenol. That doesn't work. Then they put me on a bunch of Tramadol and it didn't work. And then later on was prescribed Neurontin, and then, it went to Neurontin and Morphine. I use the Morphine every day." Both of these examples indicate that pain levels in PLWHA are diverse, yet commonly severe and unrelenting.

In the current study one participant stated, "Yeah because my doctor kind of shied away from the pain area. But too much, I have been in the hospital and seeing a neurologist. He's now convinced that I have to be on the pain meds, medication. I was like very upset. I was angry and I wanted to, I wanted to tell my doctor off. It just feels very, it makes you sad, and it makes you hurt and makes you think they don't care. You just, I think you might as well go ahead and die because they don't care." This participant had been given a range of medications when he first complained of pain to his health care provider. Some medicines were over-the-counter and then as his pain symptoms increased, he continued to complain about his discomfort, but was dismissed. Eventually,

he was admitted to a hospital where a neurologist was consulted. After a series of tests and exams were performed, he was diagnosed with a rare pain syndrome. During the time from his first complaints of pain to the diagnosis, he expressed varying levels of self-worth along with severe levels of pain; all of which negatively impacted his ability to perform life activities. During data collection, he shared using pot and cigarettes as his self-care pain management choices; however, he stated he felt isolated from his friends because of this use, "I usually sit outside and smoke cigarettes, and I stay shut in for like hours. And usually friends don't want to sit around and cigarette smoke. It would be boring with me sitting there being in pain or watch me in pain." In the current study, this is also a form of self-efficacy because it influences the choices PLWHA make to manage their chronic pain and thus the resulting pain management outcomes.

Findings from this study are similar to the findings in 1992, when O'Neil and Sherrard reviewed the symptom of pain in PLWHA as disease progression occurs and provided guidelines for specific treatments. Additionally, they advised that the treatment of the symptom of pain in this population should not be delayed. They concluded that there was no reason to assume pain management in PLWHA was different from non-HIV+ adults and advised using the WHO analgesic pain ladder as a basis for management in PLWHA. A few years later, in 2002, Evans, et al. found that the ability to relieve pain is, in part, dependent upon an individual's appraisal of his/her self worth and his/her confidence to perform life activities.

There is little research in PLWHA regarding the self-efficacy they feel in communicating their pain symptoms. In this study, participants rated their abilities to communicate with their health care providers using the "Communicating with Health Care Providers" HIV-SE subscale. For the current study, participants rated how sure or confident they were about being able to do a task regularly at the present time using a

scale of 1 (not at all sure) to 10 (totally sure), indicating that this sample of PLWHA felt they were confident in their abilities to do the difficult things necessary to manage many aspects of the chronic illness of HIV/AIDS. The study findings revealed that the participants had high self-efficacy beliefs when communicating with their health care providers about their needs on this commonly used quantitative measure. This has not been reported previously.

A female participant who has been living with HIV for 19 years, rated her pain at 8/10 on the day of data collection and reported her communication with her health care providers as "totally sure [that she could communicate with her health care providers her needs per the 4-item HIV-SE subscale]" indicating high confidence when interacting with her health care providers and for her self-care of the symptom of pain or discomfort. For pain relief, she stated, "Medicine mainly, vicodin and muscle relaxants. Yes, I can do more, when I'm not feeling bad; I'm very active; I get to cleaning." She reported she does not use other people's medications because she is "scared of trying anything unless I ask my doctor," expressing satisfaction in her health care provider and their encounters. Researchers Jacobsen, et al (2010) found similar findings in their study in non-HIV, cancer patients when communicating with their health care providers about their pain needs. Another participant described his connection to his health care provider in this way, "I holler, I call my doctor. Yeah. Even if I have to go to the emergency room, I don't take nothing until I talk to my doctor. He kept me alive. I was almost dead when I came in here." This comment shows that the participant tries to keep good, open communication between him and his health care provider so that he receives satisfactory care.

These findings are similar to those reported by Shively, et al. (2002), where their study evaluated self-efficacy for HIV disease management in 153 symptomatic HIV+

adults. For their study, the subscale "Communicating with Health Care Provider," Shively, et al. reported a mean score of 9.05 (*SD* 1.43). Furthermore, in their study, this subscale was identified as one that had higher scores than other subscales within the questionnaire.

For a different participant, there is a different point of view when interacting with health care providers for the symptom of pain. He reported a 5/10 for the HIV-SE item for how sure he was that he could "keep the physical discomfort or pain of [his] disease from interfering with the things [he] wants to do". His scores on the "Communicate with Health Care Provider" sub-scale items were each 5/10, indicating he had moderate confidence in communicating with his health care provider. However, he stated, "Now that I'm on the pain medicines, it means a lot. And I'm very grateful that my doctor continues that every month. Yeah, I mean my spirits are a little bit better. I mean, sometimes, I'm down in the dumps, depressed sometimes." With this in mind, it is important to examine both quantitative and qualitative information when delivering care to PLWHA who experience chronic pain due to the different degrees of their needs. This is an important finding which will be discussed in the next section related to the self-care and seeking care pain management choices PLWHA utilize when experiencing pain.

COPING AND PAIN MANAGEMENT CHOICES (SELF-CARE AND/OR SEEKING CARE ACTIVITIES)

The participants often reported using both self-care and/or seeking care activities to manage their pain. The sample's pain management choices (self-care and/or seeking care activities) and their confidence in performing life activities within the context of pain are important variables when describing the complex symptom of pain in this

population. If the pain management choices (self-care and/or seek care activities) effectively decrease pain, their confidence increases.

In this study, the participants' use of specific activities to manage their pain was measured using the Coping Inventory for Pain in Persons Living with HIV/AIDS. It is an investigator developed 12-item questionnaire created from a previous qualitative study which sought to explore how adults living with HIV/AIDS manage their pain. Using the Coping Inventory, participants were asked to indicate the likelihood of using each of the activities listed to manage their pain on a 5-point Likert scale. There was a range of responses for each item; however, there were 5 items that were most often used by this population: tolerate the pain (82%), take a nap (71%), watch TV or movies (63%), exercise/walk (63%), and fear the pain (60%).

While a focus of my study was not to measure taking of medications as a pain management choice, an interesting finding of the study was participant perceptions of their medications. One female who has been HIV+ for 15 years stated, "The older I got, the older I got, it [pain] got more different. I started getting pain because of my age. I'm 57 now." And she described her interaction with her health care provider, "She [her doctor] just said I'm going to give you these pills. Try this at bedtime." At her next visit while her health care provider re-assessed her pain complaints, she informed her provider that, "..[she was] not taking them. I'm only taking a PRN when I get the pain. I'm going to take them. 'No you need to take them every day, every night.' [said her provider]. I didn't think I needed to take them, only take them for the pain. But she said no. I need to take them every night because I need to get enough in my system to work."

Another participant discussed the side effects of taking prescription medications. "Being able to function with the pain without being all drugged out. Most medications make you drowsy. Sometimes, I have to skip a dose just to cook dinner or go do what I

need to do. You know, wait until once I'm in the house so I can take my medicine, so I'm not driving under the influence."

The pain management choices (self-care and/or seeking care activities) identified by the participants in this study are similar to the findings in a study conducted by Holzemer, et al (1998); however, only 5% of their sample stated using non-pharmacologic self-care activities. Within the 5% of the Holzemer et al sample though, activities such as resting and relaxation, doing nothing, and exercising were reported as frequently used by PLWHA who experienced pain. That population reported 75% effectiveness when using self-care activities to manage their pain. Additionally, 78% of the Holzemer sample reported taking pain medication as a self-care activity.

Being perceived as a 'drug seeker' was a concern voiced by some participants in the current study. One male who takes Norco daily along with neurontin stated, "..the difference between someone coming in and asking for medication that's going to abuse it and the difference of the people that, that, you know, you really need it. Because I had a hard time when I first moved here. I mean I'd go to Brackenridge, and they'd tell me you ain't getting nothing here. I mean, I'm in pain ... and they were looking at me and talking to me like I was some pill fiend or something. Like I had done something. I finally got mad and left."

One transgender participant made this comment when discussing using someone else's medications, "Oh, no, you don't do that. No, no, no. My doctor don't play that. I talk to him, and he tell me whatever I need, he'll get it. If he can't prescribe it for me, then I don't need it." When asking another participant if non-prescribed medications were ever used, she replied, "I can't do that because of my HIV … I have to get, get the right medicine from my doctor. To tell me what medicine that doesn't interfere with my HIV medicine."

With these findings in mind, drug-taking behaviors are important to evaluate. Passik and colleagues in 2000 assessed drug-taking behaviors and addiction in HIV+ patients who experienced chronic pain. Within the sample, 44% (n= 48) of the participants reported using someone else's medication and 48.7% (n= 53) reported purchasing opioids without a prescription. In this group, 53% (n=59) described themselves as recovering addicts which is often another facet of difficulty in managing the pain complaints in this population. This information relates to the current study in that participants may or may not have been taking medications are prescribed, or as intended to be taken.

Participants in the current study expressed at times no interest in taking prescribed pain medications. One stated, "No, I hate taking medicine." Most participants spoke of having their pain controlled as if it was the most important thing in their life. One shared this statement, "If I can control this pain, I would feel better altogether. That's a better feeling altogether. Give you more hope." Another stated, "That would really be a blessing to have no pain at all. Yeah. It would be like heaven."

Lastly, participants described their self-care activities when managing their pain. One participant described activities she used in combination with medications in this statement, "Heat, physical therapy, pain medication, and [I] tried to stay asleep. To relax, take some of the tension off." One male stated, "I do a lot of different things. I like to walk. I walk a lot. And one of my nieces, she's a masseuse, and she massages me. Yeah, I like that. Yes, it helps. Eventually, it comes right back, but it relaxes me some." Another participant stated, "I got up and walked. I got in the hot tub. I put a heating pad on it. I get up, I clean up, I cook. And you know, I do a lot of stuff to keep me [from being stressed in pain]. Yeah, gardening and that. Keep me from being stressed."

More self-care activities were revealed by a 47 year old female when she described what she does to manage her pain, "I start hurting; I'm just going to sit down. I'll take my medicine, um, you know, I already have patches on, so I can't put more patches on. And if I've already taken my medicine for the day, I can't take more. So I would just normally sit down and get myself comfortable, watch TV or something. Drink a cup of hot tea, green tea."

These findings were similar in Robb, et al (2006) and Nicholas, et al (2010); they found that individuals who experienced chronic pain utilized various activities to manage their pain. Robb et al concluded that chronic cancer treatment-related pain in patients is positively impacted through the use of cognitive-behavioral methods like relaxation and exercise. Nicholas, et al concluded that PLWHA who had neuropathy used 3 domains of self-care. In this study, participants reported using all three self-care domains described by Nicholas: 1) walking, taking a hot bath or not doing anything, 2) receiving acupuncture or massage, and 3) drinking alcohol or smoking cigarettes.

It is important to assess each patient on many levels when there is a complaint of pain; everything from the pain level, type, area and description of the pain to what are they doing at home to manage the pain should be assessed. This gives a broad picture which can benefit the clinician when making the diagnosis and managing the complaint.

The rapport that is built between patient and clinician develops over time and is crucial for these steps to take place. One participant shared, "They [clinicians] need to listen more. They need to listen more and take in stride what the patient is saying to them because everybody's not the same. Everybody doesn't deal with their pain. There are some of us that have a high threshold as far as pain goes. And there are some that have no threshold when it comes to pain and everything and stuff. I think it would probably be

more or less on a level where they need to spend time getting to know their patients so they would know how to handle the situation."

Another participant spoke about this partnership, "Being responsible to yourself. Taking, taking part of what's best for you or what I think is best for me. And you know just, you know, like I say, if it doesn't work for me, then I have the doctor tell me what's best for me, you know. Maybe I think it's the best. You know, professionally, maybe I need some professional help. I don't know that until I ask them."

Additionally, during the clinic encounters, one participant explained her point of view when communicating with her health care provider, "I wouldn't have any problem telling a doctor or whoever's taking care of me how I feel about this pain. I have no problem explaining to them what I go through at night when I have it. You know what I'm saying? And to find out, and I really want them to find out what really causes it. If it's not the HIV, then what is it?" Participants shared a variety of viewpoints when communicating and working in partnership with their providers. One participant stated, "..Managing my pain means that I should still be open and honest with my doctor about everything that's going on. And if he suggests on trying something new, then I should try it. You know, not be closed up to new suggestions because it's not all about a pill all the time."

From this information, it is evident that a partnership in care is necessary for positive outcomes in PLWHA who experience chronic pain. The descriptions of the factors that influence an individual's choice to use self-care activities or to seek care from a health care provider to manage his/her pain were found in this study and are a unique contribution to the body of literature describing life in PLWHA.

OUTCOMES AND CONFIDENCE IN PERFORMING LIFE ACTIVITIES WITHIN THE CONTEXT OF PAIN

PLWHA's confidence in performing life activities within the context of pain is an important variable when describing the complex symptom of pain in this population. The PLWHA sample in this study experienced chronic pain on a daily basis. Each participant made changes to his/her daily routines depending upon the level of pain his/her experienced. Confidence in performing life activities within the context of pain is dependent upon how well the PLWHA are able to manage their pain either through self-care activities and/or seeking care from health care providers. Confidence increased when their pain decreased due to the pain management choices they performed.

Using the Pain Self-Efficacy questionnaire, this study sought to describe the PLWHA's confidence in performing life activities within the context of pain. Participants' scores ranged from 4 to 60. The mean score was 36.7 (*SD* 13.7). Within the questionnaire, there were particular items of interest in relation to the PLWHA's self-efficacy in performing life activities and are described next.

Several items had high mean scores within this sample. One item, "I can enjoy things, despite the pain" had a mean score of 3.90 (*SD* 1.75) out of 6. Another, "I can still accomplish most of my goals in life, despite the pain" had a mean score of 3.66 (*SD* 1.98) out of 6 and the item, "I can gradually become more active, despite the pain" had a mean score of 3.60 (*SD* 1.89) out of 6. Lastly, one item had the highest score, "I can cope with my pain in most situations" had a mean score of 4.20 (*SD* 1.70) out of 6. This item can be associated to the Coping Inventory for Pain in Persons Living with HIV/AIDS item, "When I experience uncontrolled chronic pain, I tolerate the pain" which 82% of the sample rated higher than 3 out of 5. 71% of this study's sample also rated greater than 3 out of 5 for the item, "When I experience uncontrolled chronic pain, I take a nap" and

51% rated greater than 3 out of 5 for the item, "When I experience uncontrolled chronic pain, I do nothing". Also, the item, "When I experience uncontrolled chronic pain, I fear the pain" had a rating of greater than 3 out of 5 in 60% of the participants. These items indicated that although the participants rated most every item in the PSEQ with confidence in performing life activities, it is difficult to use self-care activities only to manage their pain. These findings are similar to the study conducted by Samwell, et al (2006) who identified patient pain level was significantly correlated with patient fear of pain ($r= 0.24$, $p< 0.01$). However, fear of pain and passive pain coping strategies (such as resting/doing nothing) did not significantly add to the variance in their model.

The findings discussed above also have similarities to those reported by Arnstein, et al (1999). Their study found that self-efficacy and pain intensity in chronic pain, non-HIV patients, contributed to the progression of pain-related disability. Therefore, Arnstein and colleagues concluded that the chronic pain patients' lack of beliefs in their capabilities to manage their pain and function in spite of their pain is a significant predictor of the degree of disability in this population. The current study findings were also similar to Asghari and Nicholas' (2001) report of a significant relationship between pain management choices (self-care and/or seek care activities) and physical disability. Therefore, the higher levels of disability were related to a higher use of pain management choices (self-care and/or seek care activities) in a non-HIV chronic pain sample.

With this in mind, the current study sought to explore the relationships between PLWHA pain management choices (self-care and/or seek care activities) and their confidence in performing life activities within the context of pain. The participants' mean scores on the Coping Inventory for Pain in Persons Living with HIV/AIDS and the Pain Self-efficacy scale were significantly positively correlated. It is difficult for PLWHA to

solely use self-care activities. Participants, through interview narratives, described often using both self-care and seeking care activities together to manage their pain.

STRENGTHS AND LIMITATIONS

Strengths

This study provides new information about the pain management experiences in PLWHA. Research on pain in PLWHA has been limited and was most often examined in the 1990s. Now that HIV/AIDS has advanced to a chronic illness status, researchers have begun to re-examine pain in this population. Participants were recruited from 3 AIDS service sites. Recall bias was minimized by obtaining self-report through the questionnaires which asked participants about their coping activities and confidence at the present time. The study used an adequate sample size of 100 participants. The sample studied was representative of the adult HIV/AIDS chronic pain population.

Most often, pain is treated in PLWHA as it is treated in adults living with cancer, despite the population differences. Several participants described that their pain management choices most often consisted of self-care activities that were assisted by prescribed or non-prescribed medications. Each participant evaluated his/her pain and confidence in performing life activities within the context of pain. The responses were as diverse as the individuals themselves. This diversity in participants and responses are a major strength in the current study.

Limitations

The sampling method was self-selected convenience sampling. The sample within the 9 counties in Central Texas was perhaps too small and localized to make generalizations about other HIV/AIDS metropolitan areas. The sample participants all

had chronic pain complaints of various kinds (heterogeneous) in various locations in their bodies.

The participants may not have accurately reflected the status of all PLWHA; however, the final sample was representative of the Central Texas HIV/AIDS population (Trochim, 2001). Data was obtained through self-report measures, which according to Polit & Beck (2004), may have accuracy and validity concerns. The data were obtained by means of self-report which can have some disadvantages including sample bias, underreporting and sample artificial augmentation of the relationships of variables. Furthermore, with regards to self-report, all variables were subjectively measured by the questionnaires and interview questions which may have implications for the internal validity of the study. All of the variables studied are only accessible through self-reporting (e.g. pain level, self-care/seeking care activities and self-efficacy).

There is no guarantee the sample responded honestly. Additionally, the self-assessment of confidence in performing life activities is less objective than performance-based measures of confidence. Generalizations of the results are limited to PLWHA with chronic pain. Thus, generalizations regarding the results to other chronically ill populations cannot be made. The generalizability of the results of this study is unclear. PLWHA who receive care from non-HIV specialized health care providers, such as those at the research site like the David Powell Clinic differ across medical centers. Moreover, chronic pain patients who qualify to receive care at pain clinics may differ from patients who are not eligible for pain specialty care.

The cross-sectional nature of this study does not allow for inference of causality between variables. Finally, the contribution of co-morbid conditions to the confidence in performing life activities was not addressed in this study.

IMPLICATIONS AND RECOMMENDATIONS

The following implications and recommendations for nursing theory, practice, education, and research are based on the main findings of this research study including: past pain experiences, health care provider stigma related to past pain management, past experiences with health care providers, self-efficacy in communicating pain needs, current pain level, pain management choices (self-care and/or seeking care activities) and confidence in performing life activities within the context of pain.

Theory

The Stress, Appraisal and Coping Model (Lazarus & Folkman, 1984) is an important theoretical model for studying the pain experiences in PLWHA. The model provided a new understanding for the variables in the model and the stressors of managing chronic pain in PLWHA. Throughout the past 26 years, since the theory's origin, it has been widely used and there has been an immense amount of research generated which has contributed and influenced education, practice and health. From research conducted, measurements and tools have been created in order to assess and quantify life events (Lazarus & Folkman, 1984). The Stress, Appraisal and Coping model has great generalizability due to the fact that it can be measured in many ways, in many different populations, across many different disciplines of research. Lastly, the model of the theory is parsimonious in that it is simple in nature and explains the complex concepts of stress, appraisal and coping. The process of understanding the stress perceptions of human beings is challenging. These are key variables of the original model.

This theoretical model helps to describe the quality of variables and experiences in PLWHA who experience chronic pain. Findings from this study support both the

original model and the conceptual model created to guide the current study. Model modifications based on the findings from this study are described below.

In this study, the historical stressors had three possible effects on PLWHA communication self-efficacy; positive, neutral or negative. This relationship was supported through data generated from the open-ended questions, the HIV-SE communicating with health care provider subscale and the PSEQ total score. Participants confirmed that there continue to be negative experiences in the lives of PLWHA when seeking care for pain management; it is just as common as it was 20 years ago. Specifically, participants reported pain management stigma and health care provider stigma that negatively influenced their self-care efficacy.

Next, it was hypothesized that the ability to appropriately relieve pain is dependent upon the individual's appraisal and self-efficacy in communicating his/her pain needs. Quantitatively (HIV-SE communication subscale scores), this sample reported high self-efficacy beliefs when communicating with their health care providers at an HIV-specialized city clinic. However, the quantitative questions did not specifically ask about pain complaints and discussions with health care providers. Participant narratives revealed a much more diverse assessment of personal abilities to communicate with health care providers.

Communication self-efficacy is also impacted by current pain levels. Participants reported that their pain levels and locations were diverse, but commonly it is severe and unrelenting as disease progression occurs. Results supported the hypothesis that both pain level and self-efficacy in communicating pain needs in PLWHA impact pain management choices.

Finally, the hypothesized relationship between pain management choices (self-care and/or seek care activities) and confidence in performing life activities was

supported. The participants' pain management choices (self-care and/or seek care activities), when effective in decreasing their chronic pain, increased their confidence in performing life activities within the context of pain. Additionally, it was found that confidence in performing life activities was dependent upon how well PLWHA are able to manage their pain through pain management choices (self-care and/or seek care activities).

Nursing Education

There are few courses in nursing education, either at the undergraduate and graduate levels, in which HIV/AIDS is discussed. These courses are commonly general pathophysiology, public health or ethics in nursing. There is always a challenge to include various chronic illnesses in nursing courses, and the experience of pain management in PLWHA may be one that individual students encounter during their clinical rotations. The results of this study support the stress, appraisal and coping model as one that can be used to describe the pain experience in PLWHA. Content about the stress of living and coping with a chronic illness, such as HIV/AIDS, needs to be included in nursing theory, aging, and chronic illness courses. Classes that highlight chronic illnesses such as diabetes, cardiac illnesses, mental health and pathophysiology of diseases should also discuss pain management. Moreover, a public health course topic that discusses the disparities in populations within healthcare due to ethnicity is necessary in order to educate future nurses about the influence of HIV/AIDS in minority populations and the cultural differences that has the disease of HIV/AIDS changing in America. Many research reports and editorial articles have been published within the past 7 years reporting how the face of this disease is no longer a young Caucasian male. It is essential for health care providers to be aware of the populations at risk for this illness to

ensure appropriate testing for HIV/AIDS when individuals present to emergency rooms or clinics with possible symptoms.

Research

The present study provides new information about the pain management experiences in PLWHA related to historical stressors, self-efficacy, pain management choices (self-care and/or seek care activities) and outcomes of confidence in performing life activities within the context of pain.

The findings of this study support the need for additional research on assessing, developing and testing both pharmacologic and non-pharmacologic (both self-care and seeking care) activities which can be taught to PLWHA by health care providers to improve the symptom of pain.

Additional research is needed concerning self-care activities, including complimentary treatments used by PLWHA who experience chronic pain. With continued research, findings will help to develop appropriate and healthy nursing interventions to assist PLWHA who experience chronic pain to manage and improve the symptoms of pain using both self-care activities and medications.

Additional research is needed in multidisciplinary approaches to pain management: through medications, self-care activities, and mental health counseling for anxiety and stress.

Knowledge concerning the variables considered in this study and the relationships between each variable is especially important to clinicians and social workers who interact with this population. It is necessary for social workers to learn to teach and encourage healthy self-care and seeking care activities when managing chronic pain in their clients with HIV/AIDS.

Continued research is necessary using both the HIV-SE and the PSEQ in the adult HIV/AIDS population to effectively assess self-efficacy and confidence in self-care/seeking care activities in this population. For the Coping Inventory for Pain in Persons Living with HIV/AIDS, further psychometric testing is recommended. These findings will be considered the foundation for future exploration of this complex experience in PLWHA. Future studies should be longitudinal in nature so that the pattern of pain and its management over time can be assessed. Longitudinal studies are needed to explore the causative relationships between pain management choices (self-care and/or seek care activities) and functional outcomes in PLWHA.

Additionally, this study has supported the importance of using both qualitative and quantitative methods to assess the complex phenomenon of pain and its management in this diverse population. .

Nursing Practice

Nurses who work with PLWHA in any setting should be aware of the symptom of pain in this chronic illness population. Continued assessment and analysis of pain complaints by health care providers are essential pre-requisites for successful pain management. Continued learning by nurses and other health care providers about common pain syndromes experienced by PLWHA such as neuropathy will be necessary. One important aspect of this would be to teach health care providers to educate patients about their disease process, medications, and self-care activities that can be performed to help manage discomfort. Good assessment, interviews, and intervention evaluation should be performed when PLWHA are being seen by a clinician for symptom management of pain. Treatment approaches need to include both non-pharmaceutical and pharmaceutical interventions.

Health care providers who are seeing PLWHA who experience chronic pain need continued education in the use of the WHO analgesic pain ladder to correctly manage chronic pain. This education includes understanding the various medications and side effects of each medication listed per step of the ladder. Clinical lack of knowledge and training on using the WHO analgesic pain ladder can lead to poor patient care, and risk unhealthy self-care behaviors with the medications prescribed.

Partnership between patients and health care providers are necessary when accurately managing the symptom of pain in PLWHA. It is critical to assess the self-care activities patients are using in order to identify healthy and unhealthy activities. This will allow for patient education of healthy activities and should unhealthy activities be used, such as substance abuse, then interventions can be begun by health care providers and patients to prevent further unhealthy actions.

Patient-centered care must become a standard of care in the HIV/AIDS population. Patient-centered care can be supportive and facilitate better communication self-efficacy for the patient. It allows the patient to see that the clinician values the pain complaints made by the patient, shows respect and encourages patient participation and trust in their care. It also creates an environment during the medical appointment where the patient's perceptive is incorporated into decision-making and responsibility for their health and medical care. Results from this study suggest that self-efficacy is an important concept for clinical practice. It can be included in patient-centered care through patient-clinician experience sharing, providing information and verbal points of view.

Clinicians must recognize their own conscious biases towards pain management and towards HIV/AIDS patients before effectively and accurately caring for this population. Moreover, clinicians must address their communication behaviors when interacting with PLWHA when they are seeking care for the symptoms of chronic pain. It

has been documented that clinicians behave and communicate differently when the patient is more or less involved or interactive in their care. Clinicians should aim to improve the involvement of patients in their health care decisions and their pain. This can be done by clinicians expressing a supportive and friendly interaction during medical appointments and offer information, request questions from the patient or ask the patient to openly express concerns about their symptoms/illness. Identifying better strategies to monitor opioid use and misuse is also an important role of the clinician. The HIV-SE and PSEQ are two questionnaires that can be used clinically to evaluate self-efficacy for specific disease management activities used by PLWHA

Clinicians can use information from this study to understand the coping strategies used by PLWHA to manage pain. These findings indicate a need for healthcare providers to move beyond quantitative measures for this complex problem.

CONCLUSION

This chapter discussed the findings of this research and the implications the findings have for theory, nursing education, research and nursing practice. In short, the findings of this study are helpful/foundation for future studies in the topic of pain management in PLWHA. The main contribution of this study was the descriptions of the factors that influence PLWHA pain management choices to use self-care and/or seeking care activities to manage their chronic pain. The findings of this investigation indicated that communication between both patient and health care provider are important and both are influenced by a variety of factors. PLWHA with chronic pain have past pain experiences, health care provider stigma related to past pain management, and past experiences with health care providers as factors. In addition, the PLWHA's self-efficacy in communicating their pain needs is a significant factor in the pain management choices

(self-care and/or seek care activities) utilized and the overall functional outcomes in this population. Longitudinal studies are needed to explore the causative relationships between management choices and functional outcomes in PLWHA. Future research is necessary to explore these relationships to find causal relationships and predictions of variables within the model.

Chronic pain in people living with HIV/AIDS has been an issue for over 20 years. Recent research estimates that by 2015, 50 percent of adults living with HIV in America will be age 50 or older (Kirk & Goetz, 2009). Currently, this disease is classified as "advanced-aging of the body" and as advances in science and research continue to improve the medications to manage HIV/AIDS, the needs of this population in regards to symptom management will only increase.

Appendices

Appendix A –IRB Approval Dissertation Study

OFFICE OF RESEARCH SUPPORT

THE UNIVERSITY OF TEXAS AT AUSTIN

P.O. Box 7426, Austin, Texas 78713 (512) 471-8871 -FAX (512 471-8873)
North Office Building A, Suite 5.200 (Mail code A3200)

FWA # 00002030

Date: **08/20/10**

PI(s): **Sabrina Q Mikan** Department & Mail Code: **NURSING SCHOOL**

Title: **Pain Management Experiences in Adults Living with HIV/AIDS**

IRB APPROVAL – IRB Protocol # **2010-07-0061**

Dear: **Sabrina Q Mikan**

In accordance with Federal Regulations for review of research protocols, the Institutional Review Board has reviewed the above referenced protocol and found that it met approval under an Expedited category for the following period of time: **08/20/2010 - 08/19/2011** . *(expires 12am [midnight] of this date.)*

Expedited category of approval:

☐ **(1)** Clinical studies of drugs and medical devices only when condition (a) or (b) is met. (a) Research on drugs for which an investigational new drug application (21 CFR Part 312) is not required. (Note: Research on marketed drugs that significantly increases the risks or decreases the acceptability of the risks associated with the use of the product is not eligible for expedited review). (b) Research on medical devices for which (i) an investigational device exemption application (21 CFR Part 812) is not required; or (ii) the medical device is cleared/approved for marketing and the medical device is being used in accordance with its cleared/approved labeling.

☐ **(2)** Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture as follows: (a) from healthy, non-pregnant adults who weigh at least 110 pounds. For these subjects, the amounts drawn may not exceed 550 ml in an 8 week period and collection may not occur more frequently than 2 times per week; or (b) from other adults and children2, considering the age, weight, and health of the subjects, the collection procedure, the amount of blood to be collected, and the frequency with which it will be collected. For these subjects, the amount drawn may not exceed the lesser of 50 ml or 3 ml per kg in an 8 week period and collection may not occur more frequently than 2 times per week.

☐ **3)** Prospective collection of biological specimens for research purposes by Non-invasive means. Examples:

(a) hair and nail clippings in a non-disfiguring manner;
(b) deciduous teeth at time of exfoliation or if routine patient care indicates a need for extraction;
(c) permanent teeth if routine patient care indicates a need for extraction;
(d) excreta and external secretions (including sweat);
(e) uncannulated saliva collected either in an un-stimulated fashion or stimulated by chewing gumbase or wax or by applying a dilute citric solution to the tongue;
(f) placenta removed at delivery;
(g) amniotic fluid obtained at the time of rupture of the membrane prior to or during labor;

(h) supra- and subgingival dental plaque and calculus, provided the collection procedure is not more invasive than routine prophylactic scaling of the teeth and the Process is accomplished in accordance with accepted prophylactic techniques;
(i) mucosal and skin cells collected by buccal scraping or swab, skin swab, or mouth washings;
(j) sputum collected after saline mist nebulization.

☐ **(4)** Collection of data through noninvasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving x-rays or microwaves. Where medical devices are employed, they must be cleared/approved for marketing. (Studies intended to evaluate the safety and effectiveness of the medical device are not generally eligible for expedited review, including studies of cleared medical devices for new indications). Examples:

(a) physical sensors that are applied either to the surface of the body or at a distance and do not involve input of significant amounts of energy into the subject or an invasion of the subject's privacy;
(b) weighing or testing sensory acuity;
(c) magnetic resonance imaging;
(d) electrocardiography, electroencephalography, thermography, detection of naturally occurring radioactivity, electroretinography, ultrasound, diagnostic infrared imaging, doppler blood flow, and echocardiography;
(e) moderate exercise, muscular strength testing, body composition assessment, and flexibility testing where appropriate given the age, weight, and health of the individual.

☐ **(5)** Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for non-research purposes (such as medical treatment or diagnosis). (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(4). This listing refers only to research that is not exempt).

☒ **(6)** Collection of data from voice, video, digital, or image recordings made for research purposes.

☒ **(7)** Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(2) and (b)(3). This listing refers only to research that is not exempt).

☐ **Please use the attached approved informed consent**

☒ **You have been granted Waiver of Documentation of Consent**
According to 45 CFR 46.117, an IRB may waive the requirement for the investigator to obtain a signed consent form for some or all subjects if it finds either:

☒ The research presents no more than minimal risk
AND
☐ The research involves procedures that do not require written consent when performed outside of a research setting
<OR>
☒ The principal risks are those associated with a breach of confidentiality concerning the subject's participation in the research
AND
☒ The consent document is the only record linking the subject with the research
AND
☒ This study is not FDA regulated (45 CFR 46.117)
AND
☒ Each participant will be asked whether the participant wishes documentation linking the participant with the research, and the participants wishes will govern.

You have been granted Waiver of Informed Consent
According to 45 CFR 46.116(d), an IRB may waive or alter some or all of the requirements for Informed consent if:

☐ The research presents no more than minimal risk to subjects;
☐ The waiver will not adversely affect the rights and welfare of subjects;

☐ The research could not practicably be carried out without the waiver; and
☐ Whenever appropriate, the subjects will be provided with additional pertinent information they have participated in the study.
☐ This study is not FDA regulated (45 CFR 46.117)

RESPONSIBILITIES OF PRINCIPAL INVESTIGATOR FOR ONGOING PROTOCOLS:

(1) Report **immediately** to the IRB any unanticipated problems.

(2) Proposed changes in approved research during the period for which IRB approval cannot be initiated without IRB review and approval, except when necessary to eliminate apparent immediate hazards to the participant. Changes in approved research initiated without IRB review and approval initiated to eliminate apparent immediate hazards to the participant must be promptly reported to the IRB, and reviewed under the unanticipated problems policy to determine whether the change was consistent with ensuring the participants continued welfare.

(3) Report any significant findings that become known in the course of the research that might affect the willingness of subjects to continue to take part.

(4) Insure that only persons formally approved by the IRB enroll subjects.

(5) Use **only** a currently approved consent form (remember approval periods are for 12 months or less).

(6) **Protect the confidentiality of all persons and personally identifiable data, and train your staff and collaborators on policies and procedures for ensuring the privacy and confidentiality of participants and information.**

(7) Submit for review and approval by the IRB all modifications to the protocol or consent form(s) prior to the implementation of the change.

(8) Submit a **Continuing Review Report** for continuing review by the IRB. Federal regulations require **IRB review of on-going projects no less than once a year** (a Continuing Review Report form and a reminder letter will be sent to you 2 months before your expiration date). Please note however, that if you do not receive a reminder from this office about your upcoming continuing review, it is the primary responsibility of the PI not to exceed the expiration date in collection of any information. Finally, it is the responsibility of the PI to submit the Continuing Review Report before the expiration period.

(9) Notify the IRB when the study has been completed and complete the Final Report Form.

(10) Please help us help you by including the above protocol number on all future correspondence relating to this protocol.

Sincerely,

Jody L. Jensen, Ph.D.
Professor
Chair, Institutional Review Board

Appendix B – Dissertation Cover Letter

Dear Participant,

Thank you for your interest in this study! You are being asked to participate in a research study. Your participation is entirely voluntary.

In this study I hope to learn about the pain management experiences of people living with HIV/AIDS (PLWHA) who have chronic pain and to learn what influences this experience. This information will help me to design new approaches health care providers can use when caring for people living with chronic illnesses like HIV/AIDS.

If you want to be in this study, I will ask you to fill out one 69-item questionnaire packet. After your fill out the packet, I will ask you if you'd like to answer 4 additional questions about your experience. The interview responses will be audio-taped. The total estimated time is about 90 minutes for both parts.

You can refuse to participate or stop participation without penalty or loss of benefits to which you are otherwise entitled. You can stop your participation at any time and your refusal will not impact current or future relationships with UT Austin or participating sites: AIDS Services of Austin, Project Transitions and the David Powell COMMUnity Care Clinic. To do so simply tell me you wish to stop. Answering questions may be uncomfortable or distressing to you, you do not have to continue with questions that make you uncomfortable.

There are no direct benefits to you for being in this study. Currently, information present to clinicians has not yet answered the questions that will be evaluated in this study. Through participating in this study, you will be contributing by advancing knowledge about people living with HIV/AIDS and the self care actions taken to manage the experience of pain described in your own words and your lived experiences.

You will receive a $10.00 gift card to H-E-B as compensation for your time completing the questionnaire packet. There is no additional compensation for answering the 4 interview questions.

Please know that completed questionnaire packets will be held in confidence and in a secure, locked location. There will be no identifying information or data from the questionnaire packets or transcripts that will be shared with anyone. Additionally, audio tapes will be held in confidence and in a secure, locked location. Authorized persons from UT Austin and members of the Institutional Review Board, have the legal right to review research records and will protect the confidentiality of those records to the extent permitted by law. All publications will exclude any information that will make it possible to identify you as a subject. Throughout the study, the researchers will notify you of new information that may become available and that might affect your decision to remain in the study.

If you have any questions about the study please ask now. If you have questions about your rights as a research participant, complaints, concerns, or questions about the research please

contact Jody Jensen, Ph.D., Chair, The University of Texas at Austin Institutional Review Board for the Protection of Human Subjects at (512) 232-2685 or the Office of Research Support at (512) 471-8871 or email: orsc@uts.cc.utexas.edu.

Faculty Sponsor:
Patricia Carter, PhD, RN, CNS, Associate Professor, University of Texas at Austin, School of Nursing:
(512)-232-4709, e-mail: pcarter@mail.nur.utexas.edu

Principal Investigator:
Sabrina Q. Mikan, RN, CNS, Doctoral Candidate, University of Texas at Austin, School of Nursing:
(512) 470-0578, e-mail: nurse2003@mail.utexas.edu

You will be given a copy of this information to keep for your records.

Sincere thanks,

Sabrina Q. Mikan, RN, ACNS, APRN-BC
Doctoral Candidate
UT Austin School of Nursing

Appendix C – Dissertation Letters of Support

June 4th 2010

Sabrina Q. Mikan, RN, CNS
Doctoral Candidate
University of Texas at Austin, School of Nursing
1700 Red River
Austin, TX 78701

Dear Sabrina Q. Mikan;

I am writing in support of your study *Pain Management Experiences in Adults Living with HIV/AIDS.* AIDS Services of Austin serves over 1,500 adults living with HIV/AIDS annually in the Austin and surrounding counties. Several of these individuals would meet your study's participation criteria.

I understand how important this research is for the physical and emotional health of adults living with HIV/AIDS, especially now that it is a chronic illness. People are living longer and facing different forms of the illness than we knew about years ago.

Your qualitative study in 2008 interviewed people with HIV who experience pain. The information you gathered and analyzed assisted you in your current study's focus. The way people cope with their pain and the actions they take to manage their pain is a complex topic, but one that is so important. This research will begin to contribute to the lack of current information about pain experienced by adults living with HIV/AIDS in turn benefiting clinicians in order to perform the finest care.

I support you in your research study and my organization will assist you in identifying possible participants.

Sincerely,

Erin A. Becnel, LMSW
Director of Access Services
AIDS Services of Austin
(t) 512-406-6123
(f) 512-452-3299

Helping Central Texans living with HIV and AIDS for 20 years.

P.O. Box 5874
Austin, TX 78763
(512) 458-2437
www.asaustin.org

CommUnityCare

Health Center Locations

A.K. Black
928 Blackson Avenue
512-978-9740

ARCH Homeless Clinic
500 E. 7th Street
(At the ARCH)
512-978-9920

David Powell
4614 N. IH-35
512-978-9100

Del Valle
3518 FM 973
512-978-9760

East Austin
211 Comal Street
512-978-9200

Manor
600 W. Carrie-Manor
512-978-9780

Montopolis
1200-B Montopolis
512-978-9800

Northeast Austin
7112 Ed Bluestein
512-978-9300
Dental: 512-978-9880

Oak Hill
8656-A Hwy 71
512-978-9820

Pflugerville
15288 Foothill Farm Loop
512-978-9840

RBJ Dental Clinic
15 Waller Street
512-978-9895

Red River
1215 Red River
Inside the Health South bldg
512-978-9940

Rosewood Zaragosa
2802 Webberville Road
512-978-9400

Rundberg
825 E. Rundberg
512-978-9600

South Austin
2529 S. First Street
512-978-9500
Dental: 512-978-9865

William Cannon
6801 IH-35
512-978-9960

June 14th 2010

Sabrina Q. Mikan, RN, CNS
Doctoral Candidate
University of Texas at Austin, School of Nursing
1700 Red River
Austin, TX 78701

Dear Sabrina Q. Mikan,

I am writing in support of your study *Pain Management Experiences in Adults Living with HIV/AIDS.* We provide extensive medical and social services for adults living with HIV/AIDS within the city of Austin and the surrounding counties and know that Pain and Pain management is a challenging area for both patients and medical providers.

It is our belief that a number of our patients would meet your study's inclusion criteria. We are willing to assist you to identify potential participants for your study but cannot guarantee how many may choose to participate. I am happy to support you in this project and hope that we can gain some valuable information.

Thank you for conducting this research that will benefit this vulnerable population.

Sincerely,

Debbie Lowndes-RN

Deborah Lowndes, RN
Regional Practice Administrator
CommUnityCare David Powell
(512) 978-9112

PROJECT TRANSITIONS INC

Doug's House
residential hospice

Roosevelt Gardens
supportive housing

Highland Terrace
independent living

Community Housing
scattered-site housing

Top Drawer Thrift
thrift store

June 3rd 2010

Sabrina Q. Mikan, RN, CNS
Doctoral Candidate
University of Texas at Austin, School of Nursing
1700 Red River
Austin, TX 78701

Dear Sabrina Q. Mikan,

I write in support of your study *Pain Management Experiences in Adults Living with HIV/AIDS*. This research is important in order to refine and advance the medical algorithms for managing the symptoms of pain in this adult population.

At Project Transitions we serve over 100 clients annually with both medical and social services, including palliative care. We understand first hand that pain is a symptom our clients often experience. It is a continually growing and changing field.

Project Transitions continues to support you in your research study and we are willing to assist you in identifying potential participants. Thank you for your dedication to this field of research.

Sincerely,

Beth Thomas

Beth Thomas, LCSW
Director of Client Services
Project Transitions
(512) 454-8646 ext. 103

Appendix D –Dissertation Questionnaire Packet

Pain Management Experiences

QUESTIONNAIRE PACKET

Hello,

Please answer the questions in the next few pages.
The directions are at the beginning of each section.

Thank you for your participation in this study.

DEMOGRAPHICS Sheet

1. What is your birth date? _____

2. You are male or female? _____

3. Which of the following is your Ethnicity/Culture?
   African-American _____ Asian_____ Hispanic_____
   Caucasian_____ Other _____

4. How many years did you go to school? _____

5. Are you working? Yes____ No_____ What is your job? _____

6. Did you quit your job because of illness? _____

7. In the past month, which of the following symptoms have you had?
   Fatigue ___ Confusion ____ Pain ___ Weight Loss _____
   Nausea/Vomiting ____ Difficulty Breathing _____ Diarrhea _____
   Other _____

8. Do you have any illnesses other than HIV? _____

9. When were you first diagnosed as HIV-positive? _____ (date)

10. Are you taking highly-active antiretroviral (HAART) medication? _____
    If so, what medications: _____
_____

11. Are you taking a prescribed pain medication or narcotics? _____
    If so, what medication: _____
_____

12. Rate your current level of Pain (circle the number below that best describes your pain):

0 1 2 3 4 5 6 7 8 9 10

Coping Inventory for Pain in Persons Living with HIV/AIDS (PLWHA):

When you experience pain, there are many activities that you can do to make the pain go away. Below is a list of activities that other people living with HIV/AIDS who experience pain have said are helpful in managing their pain on their own.

To indicate your answer circle **one** of the numbers on the scale under each item, where 1 = least likely and 5 = most likely.

Circle the number that rates what you would do.

When I experience uncontrolled chronic pain, I:

	Least Likely				Most Likely
1. Take a bath	1	2	3	4	5
2. Do nothing	1	2	3	4	5
3. Get a massage	1	2	3	4	5
4. Visit the physical therapist	1	2	3	4	5
5. Read a book or magazine	1	2	3	4	5
6. Tolerate the pain	1	2	3	4	5
7. Drink alcohol	1	2	3	4	5
8. Watch movies or TV	1	2	3	4	5
9. Take a nap	1	2	3	4	5
10. Exercise or take a walk	1	2	3	4	5
11. Fear the pain	1	2	3	4	5
12. Other things you do to manage your pain:					

4

HIV Self-Efficacy Questionnaire

Please **CIRCLE** the number that corresponds to how sure or confident you are that you can do the tasks regularly at the present time.

How sure are you that you can....	Not at all sure									Totally sure
1. Keep from getting discouraged when nothing you do seems to make a difference?	1	2	3	4	5	6	7	8	9	10
2. Do something to make yourself feel better when you are feeling discouraged?	1	2	3	4	5	6	7	8	9	10
3. Keep from feeling sad or down in the dumps?	1	2	3	4	5	6	7	8	9	10
4. Do something to make yourself feel better when you feel sad or down in the dumps?	1	2	3	4	5	6	7	8	9	10
5. Keep yourself from feeling lonely?	1	2	3	4	5	6	7	8	9	10
6. Do something to make yourself feel better when you are feeling lonely?	1	2	3	4	5	6	7	8	9	10
7. Keep your sadness or depression from interfering with what you want to do?	1	2	3	4	5	6	7	8	9	10
8. Do something to make yourself feel better when your sadness or depression interferes with what you want to do?	1	2	3	4	5	6	7	8	9	10
9. Reduce the emotional distress caused by your health condition so that it does not affect your everyday life?	1	2	3	4	5	6	7	8	9	10

5

How sure are you that you can….	Not at all sure									Totally sure
10. Follow the instructions correctly for a large number and variety of prescription medications?	1	2	3	4	5	6	7	8	9	10
11. Take your prescription medications at the appropriate timing?	1	2	3	4	5	6	7	8	9	10
12. Take medications to treat or prevent HIV or HIV-related diseases as directed?	1	2	3	4	5	6	7	8	9	10
13. Thinking about the side effect, number, and timing of these medications, how sure are you that you can take most or all of your Protease Inhibitor and/or NNRTI medications as directed?	1	2	3	4	5	6	7	8	9	10
14. Now suppose there were NO SIDE EFFECTS. Thinking about the number and timing of these medications, how sure are you that you can take most or all of your Protease Inhibitor and/or NNRTI medications as directed?	1	2	3	4	5	6	7	8	9	10
15. Take your medications everyday as they are prescribed?	1	2	3	4	5	6	7	8	9	10
16. Work with your doctor/nurse practitioner to reach agreement on the best medication for you overall?	1	2	3	4	5	6	7	8	9	10
17. Reduce your symptoms in general?	1	2	3	4	5	6	7	8	9	10
18. Keep the sleep problems caused by your disease from interfering with the things you want to do?	1	2	3	4	5	6	7	8	9	10
19. Keep the physical discomfort or pain of your disease from interfering with the things you want to do?	1	2	3	4	5	6	7	8	9	10

How sure are you that you can….	Not at all sure									Totally sure
20. Keep any other symptoms or health problems you have from interfering with the things you want to do?	1	2	3	4	5	6	7	8	9	10
21. Control any symptoms or health problems you have so that they don't interfere with the things you want to do?	1	2	3	4	5	6	7	8	9	10
22. Ask your doctor/nurse practitioner things about your illness that concern you?	1	2	3	4	5	6	7	8	9	10
23. Discuss openly with your doctor/nurse practitioner any problems that may be related to your medications?	1	2	3	4	5	6	7	8	9	10
24. Work out differences with your doctor/nurse practitioner when they arise?	1	2	3	4	5	6	7	8	9	10
25. Ask your doctor/nurse practitioner things about your medications and treatments that concern you?	1	2	3	4	5	6	7	8	9	10
26. Get information about your illness and its treatments from community resources?	1	2	3	4	5	6	7	8	9	10
27. Get family or friends to help you with the things you need (such as household chores like shopping, cooking or transportation)?	1	2	3	4	5	6	7	8	9	10
28. Get community resources to help you with the things you need (such as household chores, like shopping, cooking or transportation)?	1	2	3	4	5	6	7	8	9	10
29. Get emotional support (such as listening or talking over your problems) from friends and family?	1	2	3	4	5	6	7	8	9	10

How sure are you that you can….	Not at all sure									Totally sure
30.Get emotional support (such as listening or talking over your problems) from community resources other than friends and family?	1	2	3	4	5	6	7	8	9	10
31.Decrease your fatigue?	1	2	3	4	5	6	7	8	9	10
32.Keep fatigue caused by your disease from interfering with the things you want to do?	1	2	3	4	5	6	7	8	9	10
33.As compared with other people with your condition, how sure are you that you can manage fatigue during your daily activities?	1	2	3	4	5	6	7	8	9	10
34.How sure are you that you can deal with the frustration caused by your fatigue?	1	2	3	4	5	6	7	8	9	10

Life Activities within the Context of Pain

(Pain Self-Efficacy Questionnaire)

Please rate how **confident** you are that you can do the following things at present, **despite the pain**. To indicate your answer circle **one** of the numbers on the scale under each item, where 0 = not at all confident and 6 = completely confident.

Remember this questionnaire is not asking whether or not you have been doing these things, but rather **how confident you are that you can do them at present, despite the pain.**

	Not at all Confident						Completely Confident
1. I can enjoy things, despite the pain.	0	1	2	3	4	5	6
2. I can most of the household chores (e.g., tidying-up, washing dishes, etc.) despite the pain.	0	1	2	3	4	5	6
3. I can socialize with my friends or family members as often as I used to do, despite the pain.	0	1	2	3	4	5	6
4. I can cope with my pain inmost situations.	0	1	2	3	4	5	6
5. I can do some form of work, despite the pain. ("Work" includes housework, paid and unpaid work.)	0	1	2	3	4	5	6
6. I can still do many of the things I enjoy doing, such as hobbies or leisure activity, despite the pain.	0	1	2	3	4	5	6
7. I can cope with my pain without medication.	0	1	2	3	4	5	6
8. I can still accomplish most of my goals in life, despite the pain.	0	1	2	3	4	5	6
9. I can live a normal lifestyle, despite the pain.	0	1	2	3	4	5	6
10. I can gradually become more active, despite the pain.	0	1	2	3	4	5	6

THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY

9

Open-ended Questions:

Reflecting on a specific pain experience, please tell me:

1. Tell me about your pain level and its location.

    Sub-question: Rate your level of pain on a scale of 0 to 10 with 0 being no pain and 10 being the worst pain.

2. How did you manage your pain? Did it work?

    Sub-question: Did you ever use non-prescription or non-prescribed medications?

    Sub-question: Do you feel your pain isolated you from other people?

3. What barriers you experienced, if any when seeking pain relief?

    Sub-question: Were health care providers helpful or were health care providers not helpful when you sought care for your pain?

    Sub-question: Do you feel people living with HIV/AIDS are treated differently by health care providers when seeking care to manage the symptom of pain? If so, tell me more.

4. What does managing your pain mean to you?

    Sub-question: Is there anything you would like health care providers to know regarding living with pain and seeking effective pain management?

Appendix E – IRB Approval Pilot Study 2007

OFFICE OF RESEARCH SUPPORT & COMPLIANCE

THE UNIVERSITY OF TEXAS AT AUSTIN

P.O. Box 7426, Austin, Texas 78713 (512) 471-8871 - FAX (512 471-8873)
North Office Building A, Suite 5.200 (Mail code A3200)

FWA # 00002030

Date: **12/12/07**

PI(s): **Sabrina Q Mikan** Department & Mail Code: **NURSING SCHOOL** **D0100**

Dear: **Sabrina Q Mikan**
IRB APPROVAL – IRB Protocol # **2007-11-0053**

Title: **The Experience of Managing of Pain in Adults Living with HIV**

In accordance with Federal Regulations for review of research protocols, the Institutional Review Board has reviewed the above referenced protocol and found that it met approval under an Expedited category for the following period of time: **12/12/2007 - 12/10/2008**

Expedited category of approval:
___(1) Clinical studies of drugs and medical devices only when condition (a) or (b) is met. (a) Research on drugs for which an investigational new drug application (21 CFR Part 312) is not required. (Note: Research on marketed drugs that significantly increases the risks or decreases the acceptability of the risks associated with the use of the product is not eligible for expedited review). (b) Research on medical devices for which (i) an investigational device exemption application (21 CFR Part 812) is not required; or (ii) the medical device is cleared/approved for marketing and the medical device is being used in accordance with its cleared/approved labeling.

___(2) Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture as follows: (a) from healthy, non-pregnant adults who weigh at least 110 pounds. For these subjects, the amounts drawn may not exceed 550 ml in an 8 week period and collection may not occur more frequently than 2 times per week; or (b) from other adults and children2, considering the age, weight, and health of the subjects, the collection procedure, the amount of blood to be collected, and the frequency with which it will be collected. For these subjects, the amount drawn may not exceed the lesser of 50 ml or 3 ml per kg in an 8 week period and collection may not occur more frequently than 2 times per week.

___(3) Prospective collection of biological specimens for research purposes by Non-invasive means.
Examples:

(a) hair and nail clippings in a non-disfiguring manner;
(b) deciduous teeth at time of exfoliation or if routine patient care indicates a need for extraction;
(c) permanent teeth if routine patient care indicates a need for extraction;
(d) excreta and external secretions (including sweat);
(e) uncannulated saliva collected either in an un-stimulated fashion or stimulated by chewing gumbase or wax or by applying a dilute citric solution to the tongue;
(f) placenta removed at delivery;
(g) amniotic fluid obtained at the time of rupture of the membrane prior to or during labor;
(h) supra- and subgingival dental plaque and calculus, provided the collection procedure is not more invasive than routine prophylactic scaling of the teeth and the Process is accomplished in accordance with accepted prophylactic techniques;
(i) mucosal and skin cells collected by buccal scraping or swab, skin swab, or mouth washings;
(j) sputum collected after saline mist nebulization.

☐ (4) Collection of data through noninvasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving x-rays or microwaves. Where medical devices are employed, they must be cleared/approved for marketing. (Studies intended to evaluate the safety and effectiveness of the medical device are not generally eligible for expedited review, including studies of cleared medical devices for new indications). Examples:

(a) physical sensors that are applied either to the surface of the body or at a distance and do not involve input of significant amounts of energy into the subject or an invasion of the subject's privacy;
(b) weighing or testing sensory acuity;
(c) magnetic resonance imaging;
(d) electrocardiography, electroencephalography, thermography, detection of naturally occurring radioactivity, electroretinography, ultrasound, diagnostic infrared imaging, doppler blood flow, and echocardiography;
(e) moderate exercise, muscular strength testing, body composition assessment, and flexibility testing where appropriate given the age, weight, and health of the individual.

___(5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for non-research purposes (such as medical treatment or diagnosis). (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(4). This listing refers only to research that is not exempt).

_X_ (6) Collection of data from voice, video, digital, or image recordings made for research purposes.

_X_ (7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(2) and (b)(3). This listing refers only to research that is not exempt).

_X_ Please use the attached approved informed consent

____You have been granted Waiver of Documentation of Consent
According to 45 CFR 46.117, an IRB may waive the requirement for the investigator to obtain a signed consent form for some or all subjects if it finds either:

___ The research presents no more than minimal risk

AND

___ The research involves procedures that do not require written consent when performed outside of a research setting

<OR>

___ The principal risks are those associated with a breach of confidentiality concerning the subject's participation in the research **AND**

___ The consent document is the only record linking the subject with the research

AND

___This study is not FDA regulated (45 CFR 46.117)

AND

___Each participant will be asked whether the participant wishes documentation linking the participant with the research, and the participants wishes will govern.

____ You have been granted Waiver of Informed Consent
According to 45 CFR 46.116(d), an IRB may waive or alter some or all of the requirements for Informed consent if:

___ The research presents no more than minimal risk to subjects;
___ The waiver will not adversely affect the rights and welfare of subjects;
___ The research could not practicably be carried out without the waiver; and
___ Whenever appropriate, the subjects will be provided with additional pertinent information they have participated in the study.

___ This study is not FDA regulated (45 CFR 46.117)

RESPONSIBILITIES OF PRINCIPAL INVESTIGATOR FOR ONGOING PROTOCOLS:

(1) Report **immediately** to the IRB any unanticipated problems.

(2) Proposed changes in approved research during the period for which IRB approval cannot be initiated without IRB review and approval, except when necessary to eliminate apparent immediate hazards to the participant. Changes in approved research initiated without IRB review and approval initiated to eliminate apparent immediate hazards to the participant must be promptly reported to the IRB, and reviewed under the unanticipated problems policy to determine whether the change was consistent with ensuring the participants continued welfare.

(3) Report any significant findings that become known in the course of the research that might affect the willingness of subjects to continue to take part.

(4) Insure that only persons formally approved by the IRB enroll subjects.

(5) Use **only** a currently approved consent form (remember approval periods are for 12 months or less).

(6) **Protect the confidentiality of all persons and personally identifiable data, and train your staff and collaborators on policies and procedures for ensuring the privacy and confidentiality of participants and information.**

(7) Submit for review and approval by the IRB all modifications to the protocol or consent form(s) prior to the implementation of the change.

(8) Submit a **Continuing Review Report** for continuing review by the IRB. Federal regulations require **IRB review of on-going projects no less than once a year** (a Continuing Review Report form and a reminder letter will be sent to you 2 months before your expiration date). Please note however, that if you do not receive a reminder from this office about your upcoming continuing review, it is the primary responsibility of the PI not to exceed the expiration date in collection of any information. Finally, it is the responsibility of the PI to submit the Continuing Review Report before the expiration period.

(9) Notify the IRB when the study has been completed and complete the Final Report Form.

(10) Please help us help you by including the above protocol number on all future correspondence relating to this protocol.

Thank you for your help in this matter.

Sincerely,

Jody Jensen, Ph.D., IRB Chair

Protocol # Approval dates: - 2007-11-0053 12/12/2007 12/10/2008

Appendix F – Pilot Study Consent Form 2007

CONSENT FORM 2

IRB APPROVED ON: 12/12/2007 ***EXPIRES ON:12/10/2008***

Title **The Experience of Managing of Pain in Adults living with HIV**
IRB PROTOCOL #2007-11-0053
Conducted By: Sabrina Q. Mikan, RN, CNS
Of The University of Texas at Austin: *Nursing*; Telephone: 512-470-0578

You are being asked to participate in a research study. This form provides you with information about the study. The person in charge of this research will also describe this study to you and answer all of your questions. Please read the information below and ask any questions you might have before deciding whether or not to take part. Your participation is entirely voluntary. You can refuse to participate without penalty or loss of benefits to which you are otherwise entitled. You can stop your participation at any time and your refusal will not impact current or future relationships with UT Austin or participating sites: AIDS Services of Austin and Project Transitions. To do so simply tell the researcher you wish to stop participation. The researcher will provide you with a copy of this consent for your records.

The purpose of this study is to have a conversation about the self care actions taken to manage the experience of pain in patients with a chronic illness such as the human immunodeficiency virus (HIV). This conversation will allow the researcher to better understand patients' feelings about the pain.

If you agree to be in this study, we will ask you to do the following things:

- Participate in one 60- minute audio-taped face-to-face interview

Total estimated time to participate in study is one interview only before the date of March 1st, 2008.

Risks of being in the study

- Answering questions may be uncomfortable or distressing to participants, and if indicated the Principal Investigator will make a counseling referral.
- Participants do not have to continue with questions that make them uncomfortable.
- This interview may involve risks that are currently unforeseeable. If you wish to discuss the information above or any other concerns you may have, you may ask questions now or call the Principal Investigator listed on the front page of this form.

Benefits of being in the study

- There are no direct benefits to participants.
- Through participating in this interview you will be contributing by advancing knowledge about people living with HIV and the self care actions taken to manage the experience of pain described in their own words and their lived experiences.

Compensation:

- There will be no monetary compensation for this study.

MIKANS

CONSENT FORM 2

IRB APPROVED ON: 12/12/2007 *EXPIRES ON:12/10/2008*

Confidentiality and Privacy Protections:

- The audio tape will be held in confidence and in a secure, locked location.
- No identifying information or data from the transcripts will be shared.
- The data resulting from your participation may be made available to other researchers in the future for research purposes not detailed within this consent form. In these cases, the data will contain no identifying information that could associate you with the results, or with your participation in any study.
- If the researcher should observe or otherwise learn of child or elder abuse, confidentiality will be broken: state law requires the reporting of abuse to relevant agencies (Child Protective Services or the Texas Department of Family and Protective Services).

The records of this study will be stored securely and kept confidential. Authorized persons from The University of Texas at Austin, members of the Institutional Review Board, and (study sponsors, if any) have the legal right to review your research records and will protect the confidentiality of those records to the extent permitted by law. All publications will exclude any information that will make it possible to identify you as a subject. Throughout the study, the researchers will notify you of new information that may become available and that might affect your decision to remain in the study.

Contacts and Questions:

If you have any questions about the study please ask now. If you have questions later, want additional information, or wish to withdraw your participation call the researchers conducting the study. Their names, phone numbers, and e-mail addresses are listed below. If you have questions about your rights as a research participant, complaints, concerns, or questions about the research please contact Jody Jensen, Ph.D., Chair, The University of Texas at Austin Institutional Review Board for the Protection of Human Subjects at (512) 232-2685 or the Office of Research Support and Compliance at (512) 471-8871 or email: orsc@uts.cc.utexas.edu.

Faculty Sponsor:
Deborah Voker, RN, PhD, Associate Professor, University of Texas at Austin, School of Nursing:
(512)-471-9088, e-mail: dvolker@mail.nur.utexas.edu

Principal Investigator:
Sabrina Q. Mikan, RN, CNS, Doctoral student, University of Texas at Austin, School of Nursing:
(512) 470-0578, e-mail: nurse2003@mail.utexas.edu

You will be given a copy of this information to keep for your records.

MIKANS

CONSENT FORM 2

IRB APPROVED ON: 12/12/2007 ***EXPIRES ON:12/10/2008***

Statement of Consent:

I have read the above information and have sufficient information to make a decision about participating in this study. I consent to participate in the study.

Signature:_____ Date: _____

_____ Date: _____
Signature of Person Obtaining Consent

Signature of Investigator:_____ Date: _____

MIKANS

Appendix G – Pilot Study Letters of Support 2007

AIDS SERVICES OF AUSTIN

November 2, 2007

Sabrina Q. Mikan, RN, CNS
Doctoral Student
University of Texas at Austin, School of Nursing
1700 Red River
Austin, TX 78701

Dear Sabrina Q. Mikan;

I am writing in support of your study *The Experience of Managing Pain in Adults Living with HIV.* This area of work is very important for the health and well being of adults living with HIV. One question that we face is how much unmanaged pain impacts the individual. Research is lacking in the field of self care actions related to the pain experience within this population. I am very happy to support you in this project.

Our organization serves numerous adults living with HIV/AIDS per year and several of these individuals would meet your study's participation criteria. In order to contribute to further research in this population and their well being, our organization will assist you in identifying possible participants. Thank you for being a leader in this area of research to improve the quality of life in this population.

Sincerely,

Julie M. Garcia, LCSW
Director of Client Eligibility Services
AIDS Services of Austin

PROJECT TRANSITIONS INC

Doug's House
residential hospice

Roosevelt Gardens
supportive housing

Highland Terrace
independent living

Community Housing
scattered-site housing

Top Drawer Thrift
thrift store

October 30, 2007

Sabrina Q. Mikan, RN, CNS
Doctoral Student
University of Texas at Austin, School of Nursing
1700 Red River
Austin, TX 78701

Dear Sabrina Q. Mikan,

I am writing in support of your study *The Experience of Managing Pain in Adults Living with HIV.* This area of work is so important for the health and well being of adults living with HIV. Pain is a complaint heard often by our staff and using the available resources within the community is an essential in our pain management efforts. There is a lack of research studies that have focused on providing an individual voice describing the self care actions taken when pain is experienced.

I would be happy to support you in this project in any way possible. We provide extensive services for people living with HIV/AIDS within Central Texas. It is our belief that a number of our clients would meet your study's inclusion criteria. We are willing to assist you to identify potential participants for your study.

Thank you for your willingness to conduct this important research that will surely benefit a truly underserved population.

Sincerely,

Sarah Shaw
Director of Special Projects
Project Transitions

Appendix H –Demographics Sheet & Interview Questions Pilot Study 2007

DEMOGRAPHICS Sheet

1. Age _____ years

2. Gender: 1. Male___ 2. Female ___ ___

3. Ethnicity/Culture:
   1. African-American ___ 2. Asian-American___ 3. Hispanic-American___
   4. Caucasian-American_____ 5. Other _____

4. Religion: 1. Christian ____ 2. Jewish ____ 3. Other _____

5. Education _____ years

6. Occupation (or occupation prior to retirement) _____

7. Did you quit your job because of illness? 1. No ___ 2. Yes ___

8. In the past month, which of the following symptoms have you had?
   1. Fatigue ___ 2. Confusion ____ 3. Pain ___ 4. Weight Loss _____
   5. Nausea/Vomiting ____ 6. Difficulty Breathing _____ 7. Diarrhea _____
   8. Other _____

9. Do you have any other illnesses?
   1. Cardiac ____ 2. Lung ___ 3. Arthritis ___ 4. Diabetes ___
   5. Hypertension ___ 6. Other _____

10. When were you first diagnosed as HIV-positive? _____ (date)

11. Are you taking highly-active antiretroviral (HAART) medication? _____
If so, what medications: _____
_____

12. Are you taking a prescribed pain medication or narcotics? _____
If so, what medication: _____
_____

Open-Ended Questions:

1. Can you describe how you manage your pains?
2. Are there any other things you do to manage your pain?
3. Describe barriers you have experienced when seeking pain management.
4. Describe what managing your pain means to you.

Appendix I – Closure of Study Letter Pilot Study 2007

OFFICE OF RESEARCH SUPPORT

THE UNIVERSITY OF TEXAS AT AUSTIN

P.O. Box 7426, Austin, Texas 78713 (512) 471-8871 -FAX (512 471-8873)
North Office Building A, Suite 5.200 (Mail code A3200)

FWA # 00002030

Date: **01/15/09**

PI(s): **Sabrina Q Mikan** Department & Mail Code: **NURSING SCHOOL**

Title: **The Experience of Managing of Pain in Adults Living with HIV**

IRB APPROVAL – IRB Protocol # **2007-11-0053**

Dear: **Sabrina Q Mikan**

This letter is sent to you to inform you of the official closure of the above study as of **01/10/2009**. According to federal regulation 45 CFR 46.115(b), you are required to keep copies of your research records for a period of three years. The same regulation requires the IRB to maintain for three years IRB records regarding this study. During this time, all records must be kept accessible for inspection and copying by authorized representatives. Please feel free to call this office, if you have any questions.

Sincerely,

Jody L. Jensen, Ph.D.
Professor
Chair, Institutional Review Board

Appendix J – Submitted Abstract Pilot Study 2007

The Experience of Managing Pain in Adults Living with HIV

Sabrina Q. Mikan, RN, CNS Doctoral Candidate, UT Austin, School of Nursing

There is a lack of understanding how people living with HIV/AIDS (PLWHA) manage pain experiences. Treatment of pain in PLWHA broadly follows the World Health Organization's criteria for treating pain in cancer patients. However, for PWLHA pain is multifactorial. Due to gaps in the literature, there is a lack of understanding the individual's pain management activities because sensitivity of pain is perceived differently by each individual. Through researching the individual lived experience of managing pain in PLWHA, there can be more knowledge gained for better prevention and management of pain.

Purpose: The purpose of this qualitative descriptive study is to elicit narratives regarding the self care actions taken to manage the experience of pain in adults living with HIV to better understand patient pain experiences. Individuals will be asked to describe the self care actions taken when pain is experienced, barriers to pain management and what managing pain symptoms means to them. The specific aims are as follows: (1) to explore how adults living with HIV manage their pain, (2) to explore barriers adults living with HIV encounter when seeking pain management and (3) to explore the individual's perceptions of pain management and the impact of the pain experience on psychosocial and/or physical outcomes in patients living with HIV.

Methods: A 60 minute audio taped interview of 4 people living with HIV/AIDS. For this study, the researcher used qualitative content analysis based on Miles and Huberman's (1994). The researcher collected the data; performed data reduction (coding)

and data display (matrix), then reviewed the findings by meeting with an expert in qualitative data analysis to summarize the findings.

Findings: Through data reduction and display, there were 11 categories assembled from the data analysis describing these individual's experiences of managing pain. Categories were transformed into 4 main themes: "Pain Basics," "Barriers for Trust," "Strategies for Managing Pain," and "Making Meaning from Pain." *Pain Basics* signifies the physical pain experienced by PLWHA. *Barriers for Trust* signifies the healthcare provider behaviors, interactions and system which are obstacles in proper pain management for PLWHA. *Strategies for Managing Pain* signifies activities of self care and use of resources to cope with the pain utilized by PLWHA. *Making Meaning from Pain* signifies the desire for proper pain management in order to have quality of life.

Conclusions: There are several nursing implications for health care providers (HCPs) who work with PLWHA. Themes that PLWHA revealed have shown how interactions and perceptions when experiencing pain lead to certain choices when coping with pain. In many cases no partnership occurred between the PLWHA and the HCPs that made each person cope with pain in unique ways. Understanding the themes concluded from the perspectives of this population is important and will allow HCPs to deliver proper and non-biased care. With this gained knowledge, there is a need to further investigate the complicated interactions and outcomes of pain management in PLWHA and their HCPs.

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